

# **DISSERTATION**

## **The Essential Structure of Self-reported Needs of Adolescents with ADHD: A phenomenological study**

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**Submitted in part fulfilment of the degree of Master of Science in Nursing,**

**The Royal College of Nursing Institute, London**

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#### **Statement of authorship**

This dissertation is submitted to the RCN Institute in part fulfilment of the MSc in Nursing and has been conducted and presented solely by myself. I have not made use of other people's work (published or otherwise) and presented it here, without acknowledging the source of all such work.

Date 25.05.07

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Áslaug Birna Ólafsdóttir

## Abstract

This study was undertaken in 2006–2007, as part of a master's programme in nursing at the Royal College of Nursing Institute of Higher Education in London, in collaboration with the University of Akureyri.

The aim was to increase understanding of the lived experiences of adolescents with ADHD with emphasis on their self-reported needs – from their own perspective. This study is a phenomenological one within the Vancouver School which is an interpretive-constructivist school of doing phenomenology.

The sample consisted of ten adolescents aged from 11 to 16 years old in 2006, with ADHD, who were living in Iceland. I met eight of the young people once and two of them twice, resulting in a total of 12 dialogues. The essential structure of the phenomenon was constructed firstly by understanding the individual cases and then by understanding them as a whole.

The young people's accounts revealed a multifaceted reality: firstly, their need for intimacy and closeness; secondly, their need for knowledge and understanding – not prejudice; thirdly, their need to be supported, at home, at school and by peers and pets; and finally, their need for a positive self-image with self-knowledge and knowledge about ADHD, for the identification of strengths and building on them, and for optimism, faith and hope. The overriding theme describing the needs of the young people was constructed as *the need to be accepted as you are*.

This and other studies show that it can be difficult to be a young person with ADHD, not least in elementary school. The problems that young people with ADHD experience at school have a huge impact on their lives, often in the most detrimental sense, resulting in negative self-perception and unhappiness. However, the young people also exhibit many great strengths, interests and talents, and it is extremely important for their health and well-being that they should build on these in order to experience positive feelings and develop a strong self-image. Furthermore, they can be supported effectively by parents, peers and pets, elder brothers and sisters, caring teachers and school nurses. It is our moral duty to care for children with ADHD in order to ensure that they achieve the best possible development. We need to 'look through their eyes', listen to them and hear them, and fulfil their *need to be accepted as they are*.

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# Contents

<b>1. Introduction.....</b>	<b>10</b>
1.1. Aim and research question.....	10
1.2. Background to the study.....	10
1.3. Significance for nursing and the researcher's position .....	11
1.4. Summary .....	13
<b>2. Literature review .....</b>	<b>14</b>
2.1. Introduction.....	14
2.2. Literature search.....	14
2.3. Literature review .....	15
2.3.1. Young people's world of experiences.....	15
2.3.2. Young people with ADHD.....	17
2.3.3. Needs.....	19
2.3.4. Key terms .....	21
2.3.5. Summary .....	22
<b>3. Research design: methodology and methods .....</b>	<b>23</b>
3.1. Introduction.....	23
3.2. Research paradigm and rationale .....	23
3.3. Phenomenology.....	25
3.4. Hermeneutic phenomenology .....	26
3.5. Vancouver School of doing phenomenology.....	28
3.6. Methods: Sampling, data collection and data analysis .....	30
3.7. Sampling .....	30
3.8. Data collection .....	31
3.9. Data analysis .....	31
3.10. Trustworthiness .....	32
3.11. Ethics in research with young people .....	33
3.12. Summary .....	34

## **4. Data collection and analysis ..... 35**

4.1.	Introduction .....	35
4.2.	Access and permission for data collection .....	35
4.3.	The population and the sample .....	36
4.4.	Data collection .....	38
4.5.	Data analysis .....	40
4.6.	Ethics.....	41
4.7.	Trustworthiness – the rigour of the study .....	42
4.8.	Summary .....	43

## **5. Findings..... 44**

5.1.	Introduction .....	44
5.2.	A phenomenological description – an overview of the findings.....	44
5.3.	The needs of young people with ADHD in early and middle adolescence – from their own perspective.....	47
5.3.1.	The need for intimacy and closeness .....	48
5.3.1.1.	The need for intimacy and closeness with parents and custodians.....	48
5.3.2.	The need for knowledge and understanding – not prejudice .....	51
5.3.2.1.	The need to be forgiven – not judged.....	52
5.3.3.	The need to be supported .....	52
5.3.3.1.	The need to be supported at home.....	53
5.3.3.2.	Emotional support from peers and pets.....	54
5.3.3.3.	The need for support at school .....	57
5.3.3.3.1.	The need for caring teachers .....	59
5.3.3.3.2.	The need for a caring school nurse .....	60
5.3.3.3.3.	Support and help when it is needed – at an early age .....	61
5.3.4.	The need for a positive self-image .....	62
5.3.4.1.	The need for self-knowledge.....	62
5.3.4.2.	The need to identify one’s own strengths and build on them ...	64
5.3.4.3.	The need for optimism, hope and faith .....	66

5.4.	Summary .....	67
<b>6.</b>	<b>Discussion.....</b>	<b>68</b>
6.1.	Introduction .....	68
6.2.	The need to be accepted as you are .....	68
6.3.	The need for intimacy and closeness with parents.....	70
6.4.	The need for emotional support .....	72
6.5.	The need for caring teachers .....	75
6.6.	The need for a caring school nurse .....	77
6.7.	Limitations and strengths of the study .....	78
6.8.	Summary .....	80
<b>7.</b>	<b>Conclusion.....</b>	<b>81</b>
7.1.	Recommendation for practice .....	81
7.2.	Recommendation for further research.....	82
<b>Appendices.....</b>	<b>83</b>	
Appendix I.....	84	
Information about the study to the president of ADHD Association – English version/Icelandic version .....	84	
Appendix II .....	87	
A letter from the National Bioethics Committee .....	87	
Appendix III.....	90	
A framework for interviews – English version/Icelandic version .....	90	
Appendix IV .....	95	
A letter to the National Bioethics Committee – English version/Icelandic version.....	95	
Appendix V .....	98	
Approval from the Bioethics Committee .....	98	
Appendix VI.....	100	



Advertisement about the study to the prospective co-researcher – English version/Icelandic version .....	100
Appendix VII .....	105
Information about the study to the co-researchers – English version/Icelandic version .....	105
Appendix VIII .....	112
Notification to the Data Protection Authority – English version/Icelandic version .....	112
Appendix IX.....	121
Informed consent form – English version/Icelandic version .....	121
Appendix X .....	126
Declaration from the English translator .....	126
<b>References .....</b>	<b>128</b>

<b>Bibliography .....</b>	<b>143</b>
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## Figures

Figure 2.1 Temporal overlapping of literature search, data collection and data analysis in the Vancouver School. ....	14
Figure 2.2 Maslow’s hierarchy of needs.. ....	20
Figure 3.1 The process of doing phenomenology in the Vancouver School.....	28

## Tables

Table 2.1 Diagnostic criteria for ADHD.....	18
Table 3.1 The 12 basic steps of the Vancouver School .....	29
Table 4.1 Characteristics of the young people. ....	37
Table 5.1 Self-reported needs of adolescents with ADHD. ....	47
Table 5.2 The need for support at school. ....	57

# **1. Introduction**

The purpose of this research is to explore the lived experiences of adolescents with Attention-Deficit/Hyperactivity Disorder (ADHD), with emphasis on their self-reported needs – from their own perspective. The study was undertaken in 2006–2007, as part of a master’s programme in nursing at the Royal College of Nursing Institute of Higher Education in London, in collaboration with the University of Akureyri. In this introductory chapter I will present the aim and the research question. I will then describe the background to the study, and finally its significance for nursing and the researcher’s position.

## **1.1. Aim and research question**

The aim is to gain an insight into and understanding of the lived experiences of adolescents with ADHD with emphasis on their self-reported needs – from their own perspective.

The research question is: What is the lived experience of ADHD from the perspective of adolescents with emphasis on their self-reported needs?

## **1.2. Background to the study**

According to the Icelandic Directorate of Health (2003), mental-health problems among children and adolescents are rapidly increasing in Iceland. About 15–20% of Icelandic children and adolescents have mental-health problems (Iceland, Ministry of Health and Social Security, 2004). Evidently, 3–5% of this group has Attention-Deficit/Hyperactivity Disorder (ADHD) (Baldursson et al., 2000). ADHD is one of the most common neuropsychiatric disorders in childhood and these

young people make up approximately 50% of referrals to child and adolescent mental-health clinics (Jonsdottir, 2006). Furthermore, a recent Icelandic report indicates that of all children with special needs, young persons with ADHD are the group in most need of an increased health-care service in schools (Iceland, Primary Health Care of the Capital Area, 2005).

In the stated aims of the Icelandic Ministry of Health and Social Security (2001), to be achieved before 2010, priority is to be given to increasing mental-health services for children and adolescents. Emphasis is also to be placed on the primary services provided in the community, such as the public health-care service, social services and school services (Iceland, Ministry of Health and Social Security, 2004). The Primary Health Care of the Capital Area has also stated its aims for the future in terms of increased services for children/adolescents who are mentally ill (Iceland, Primary Health Care of the Capital Area, 2002).

Children and adolescents are important users of health services and it is important to gather information from them when assessing and planning for their needs (Kroll et al., 2000). Also, it is their right to express their views and wishes on matters affecting them (United Nations Convention on the Rights of the Child, 1989). However, in practice they are seldom consulted as health-care consumers (Hart and Chesson, 1998).

### **1.3. Significance for nursing and the researcher's position**

It can be argued that Icelandic society is not friendly towards children and families with children. The society has changed rapidly over the last few decades and shows signs of increased stress (Iceland, Directorate of Health, 2003). In Iceland family life has undergone far-reaching changes and today most mothers as well as fathers work outside the home. Furthermore, in Iceland parents experience a much heavier workload than is usual in other

European countries (European Communities, 2004). The divorce rate is rising, and many people establish new families more than once in their lives (Iceland, Directorate of Health, 2003), sometimes resulting in complicated relations that are difficult for children and other family members to cope with (Steinþórsdóttir and Eydal, 2001). Is it possible that some of the difficulties children with ADHD and their parents are dealing with on a day-to-day basis are in fact unsolved sociological problems in Icelandic society, some perhaps defined as mental illnesses (cf. Iceland, Ministry of Health and Social Security, 2004)?

Service needs in elementary schools have changed enormously in recent years, in keeping with rapid developments in our modern western society. The duties of school nurses are evolving from performing physical examinations to helping young people deal with their behavioural problems and feelings of unhappiness and sadness (Iceland, Ministry of Health and Social Security, 2004). In Iceland, school nurses at most elementary schools are based on site and are thus accessible to children and their parents. This puts them in a good position to help families deal with the needs of the young people, in collaboration with other school personnel such as teachers and counsellors (Kendall et al., 2005; Frame et al., 2003).

In my job as a school nurse caring for these children I observed how their behavioural problems affected the whole school environment and how people had difficulty in understanding their behaviour and problems at school. Furthermore, the parents of children with ADHD were as confused as their offspring when it came to trying to understand the condition. This immense lack of understanding awakened my interest as I believe that in our society many meanings are taken for granted in relation to the issues of children and adolescents with ADHD (Cohen, 1987) and have become accepted as values or as part of our culture. One example is when it is taken for granted that children/adolescents who are hyperactive and disruptive have been badly brought up by their parents. In my opinion, the

voices of children and adolescents with ADHD need to be heard in our society. We need more knowledge and understanding about young people with ADHD – from their own perspective.

I believe this study will be of greatest significance for nursing, in that it will help school nurses to develop and improve their nursing care by enhancing their understanding of the lives of adolescents with ADHD, both in terms of the problems they are dealing with and the solutions they have worked out – from the adolescent's own perspective.

#### **1.4. Summary**

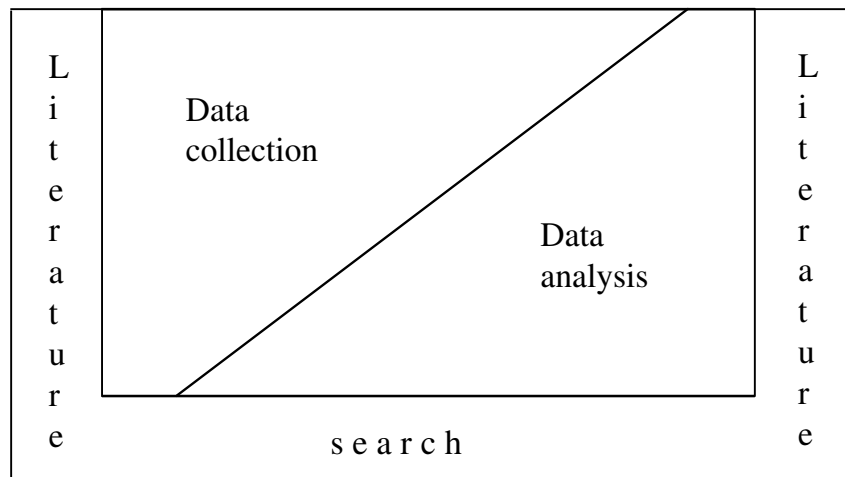
The research question is: What is the lived experience of ADHD from the perspective of adolescents with emphasis on their self-reported needs? In my opinion, there is an immense lack of understanding about the experiences of young people with ADHD in our society. Also, many meanings are taken for granted and have become accepted as values or as part of our culture. The voices of children and adolescents with ADHD need to be heard in our society, because we need more knowledge about their lives and experiences. Moreover, this study will be of importance for nursing, in that it can help nurses to develop and improve their nursing care for children and adolescents with ADHD.

## 2. Literature review

### 2.1. Introduction

In the first chapter I introduced the background to the study and the research question: What is the lived experience of ADHD from the perspective of adolescents with emphasis on their self-reported needs? In this chapter I will describe the literature search before going on to discuss the relevant literature. Finally I will present the key terms for the study.

### 2.2. Literature search



**Figure 2.1** Temporal overlapping of literature search, data collection and data analysis in the Vancouver School (Halldorsdottir, 2000, p.62).

In carrying out this study I was guided by the Vancouver School of doing phenomenology. In the Vancouver School the literature search runs concurrently with data collection and data analysis (see Figure 2.1). Therefore, as the findings in the study matured and grew, so the literature search also grew, with new keywords and searches in new databases. The searches included electronic databases

(CHINAHL, MEDLINE, Eric, OVID, ProQuest 5000, Synergy (Blackwell)), applying the search terms ‘young people and adolescents and children’ ‘ADHD’, ‘mental illness’, ‘mental disorder’, ‘phenomenology’, ‘qualitative research’ ‘young people’s views’ and ‘psychiatry’ and ‘needs’. I searched in ‘social science’, ‘psychology’ and ‘education’, as the findings gave me ideas for new issues to consider. I also applied the terms: ‘depression’, ‘sadness’, ‘behaviour difficulties’, ‘self-worth’, ‘self-image’, ‘self-perception’. Finally, I carried out a manual search of article reference lists especially in the journal *Child: Care, Health and Development*.

### **2.3. Literature review**

During my literature search I became aware that ADHD in children and adolescents has been approached from various perspectives, e.g. the nursing, medical, social-behavioural, psychological, educational and the ethical perspective. Furthermore, ADHD has been studied from the perspective of parents (mothers), teachers and school personnel, as well as from the perspective of health-care professionals such as nurses. However, I did not find many studies where ADHD is explored from the perspective of the adolescents themselves, nor any where the *needs* of adolescents with ADHD are explored from their own perspective.

#### **2.3.1. Young people’s world of experiences**

Studies of children and adolescents have a long history (Kortesluoma, 2003). However, the literature consists mainly of studies *of* young people rather than *with* young people as the assumption has been that young persons are unable to understand and describe their world and life experiences due to their developmental immaturity. Researchers have therefore almost exclusively depended on adults, i.e. parents or teachers, when collecting data about

children's and adolescents' experiences, thoughts and feelings (Kortesluoma, 2003; Morison, 2000). Hence, researchers are now increasingly recognizing the importance of directly recording young people's own perspectives (Coyne, 1998). Children are very special people (Greig and Taylor, 1999) with some intrinsic human quality independent of biological age (Kortesluoma et al., 2003), and in the qualitative dialogue it is possible to obtain data about the child that is otherwise unavailable (Morison et al., 2000). Furthermore, children's world of experiences has been inadequately studied from the point of view of nursing, although it is of most significance for nurses since it will help them to understand children and improve their nursing care by making it more child-centred (Kortesluoma et al., 2003).

The "lifeworld" of physically disabled children was explored by Mulderij (1996) in a phenomenological study and highlighted the perspective of the disabled child him- or herself. The findings centred on three themes: the body, friends, and parents and experts. In addition, the findings stressed the importance of positive feelings about the body and physical competence instead of learned helplessness, and the importance of peers and social competence. In a qualitative study Lightfoot et al. (1999) explored the support in schools for ill or disabled children, using semi-structured interviews with 33 mainstream secondary school pupils, aged 11–16 years old, with a chronic illness or physical disability that was judged to have an impact on their school life. The findings showed the importance of support from parents, teachers and close friends for the successful management of the impact of their health condition on their school life. Some of the young people's difficulties resulted from teachers' reactions to their illness or disability and from peer relationships. Finally, Lightfoot et al. (1999) found some ways for the health professionals to support the pupils both directly and indirectly, through helping others in the school to understand the children's condition and its impact on their school life.



### **2.3.2. Young people with ADHD**

ADHD is a familial disorder with an approximately fivefold greater frequency among the brothers, sisters or parents of a person with ADHD than among the general population (Valdimarsdóttir et al., 2005; Stevenson et al., 2005). Furthermore, ADHD is a complex disorder classified by symptoms of inattention and hyperactivity/impulsivity in two or more settings (e.g. home and school) (Daley, 2006) (see Table 2.1). Inattention and/or hyperactivity-impulsivity behaviour put young people and adolescents with ADHD at significant risk of a number of emotional and social problems (Kendall et al., 2005). One of the greatest difficulties they experience is adjusting to the demands of school, and they are consequently more likely to drop out of school than their classmates (Barkley, 1995).

Adolescents with ADHD are more likely to engage in high-risk behaviours, such as early regular smoking (Lambert and Hartsough, 1998), drug use and sexual activity, than their non-ADHD peers, and in addition they are at greater risk of early parenthood (Barkley et al., 2004; Barkley et al., 2006). Young people with ADHD have greater social impairment than their peers, fewer close friends and more problems with keeping friends (Barkley et al., 2006). They are aware of their negative social status (Li et al., 1995), have poorer self-perception than their peers (Frame et al., 2003; Dumas and Pelletier, 1999) and experience feelings of sadness and loneliness following peer rejection (Asher and Wheeler, 1985). They also exhibit more depressive symptoms than healthy young people (LeBlanc and Morin, 2004). They are at a higher risk of accidental injury (Hartsough and Lambert, 1985; Rowe et al., 2004), antisocial activities (Barkley et al., 2004) and completed suicide (James et al., 2004) than their peers. Moreover, in their adult life they have more psychiatric problems than their peers (McGough, 2005) as well as completing fewer years of education and experiencing more difficulties in sustaining employment in any single job for as long as their peers (Barkley et al., 2006). Current treatments for ADHD include stimulants and other types of medication, as well as psychosocial treatments such as educational counselling and support, parental training and education, coaching and alternative interventions (Barkley, 1998; Barbaresi, 2005).

## **Diagnostic criteria for Attention-Deficit/Hyperactivity Disorder**

A. Either (1) or (2):

(1) six (or more) of the following symptoms of **inattention** have persisted for at least 6 months to a degree that is maladaptive and inconsistent with developmental level:

### **Inattention**

- (a) often fails to give close attention to details or makes careless mistakes in schoolwork, work, or other activities
- (b) often has difficulty sustaining attention in tasks or play activities
- (c) often does not seem to listen when spoken to directly
- (d) often does not follow through on instructions and fails to finish schoolwork, chores, or duties in the workplace (not due to oppositional behaviour or failure to understand instructions)
- (e) often has difficulty organizing tasks and activities
- (f) often avoids, dislikes, or is reluctant to engage in tasks that require sustained mental effort (such as schoolwork or homework)
- (g) often loses things necessary for tasks or activities (e.g. toys, school assignments, pencils, books, or tools)
- (h) is often easily distracted by extraneous stimuli
- (i) is often forgetful in daily activities

(2) six (or more) of the following symptoms of **hyperactivity-impulsivity** have persisted for at least 6 months to a degree that is maladaptive and inconsistent with developmental level:

### **Hyperactivity**

- (a) often fidgets with hands or feet or squirms in seat
- (b) often leaves seat in classroom or in other situations in which remaining seated is expected
- (c) often runs about or climbs excessively in situations in which it is inappropriate (in adolescents or adults, may be limited to subjective feelings of restlessness)
- (d) often has difficulty playing or engaging in leisure activities quietly
- (e) is often "on the go" or often acts as if "driven by a motor"
- (f) often talks excessively

### **Impulsivity**

- (g) often blurts out answers before questions have been completed
- (h) often has difficulty awaiting turn
- (i) often interrupts or intrudes on others (e.g. butts into conversations or games)

B. Some hyperactive-impulsive or inattentive symptoms that caused impairments were presented before age 7 years.

C. Some impairment from the symptoms is present in two or more settings (e.g. at school [or work] and at home).

D. There must be clear evidence of clinically significant impairment in social, academic, or occupational functioning.

E. The symptoms do not occur exclusively during the course of a Pervasive Developmental Disorder, Schizophrenia, or other Psychotic Disorder and are not better accounted for by another mental disorder (e.g., Mood Disorder, Anxiety Disorder, Dissociative Disorder, or a Personality Disorder).

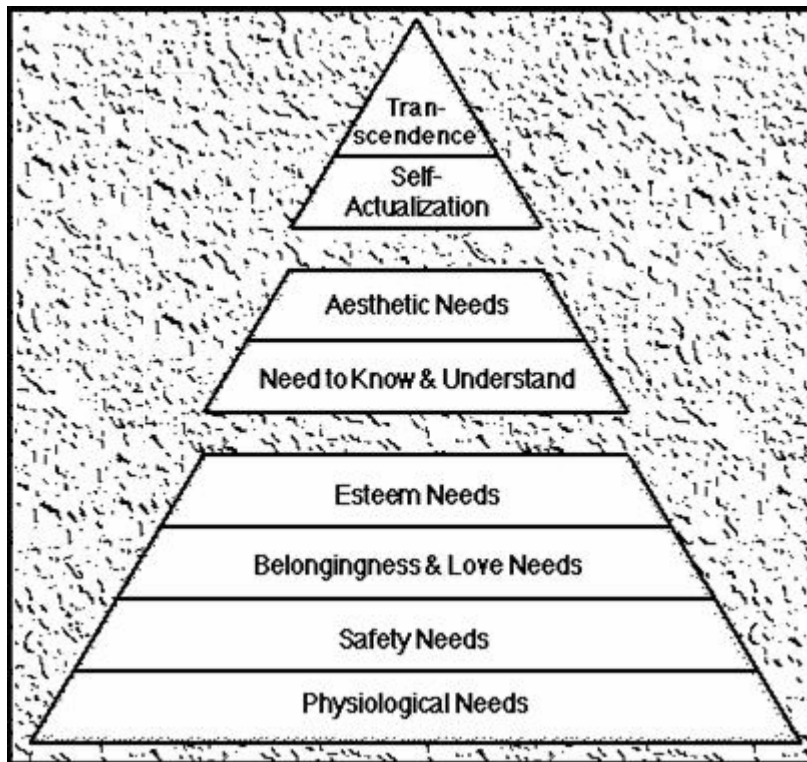
**Table 2.1** Diagnostic criteria for ADHD © American Psychiatric Association, 2000.

### **2.3.3. Needs**

Need is a concept commonly understood as a fundamental concern for the provision of health and social care of which nursing is a part (Sheppard and Woodcock, 1999; Holmes and Warelw, 1997). Within the paradigm of relativism the concept of need is seen as a relative concept which will vary over time following changes in society (Sheppard and Woodcock, 1999). What is recognized as a 'need' is affected by the values accepted within the group or society the person is living in (Sheppard and Woodcock, 1999). In nursing, needs have been explained as being context dependent, with needs of one person always differing from needs of another (Holmes and Warelw, 1997). Assistance with the satisfying of human needs has been referred to as one of the 'carative factors' serving as a guide to the 'core of nursing' (Watson, 2006).

Most nursing literature refers to specific patient needs, usually using Maslow's hierarchy as a basis (Holmes and Warelw, 1997) (see Figure 2.2). Maslow (1943) explains human needs as a hierarchy of 'deficiency needs' and 'growth needs'. Each of the lower deficiency needs must be satisfied before moving up to the next level, and when the deficiency needs are met the individual can act on the growth needs. According to Maslow, the first two levels of needs are physiological needs and safety needs. The third level is social needs; the need to feel a sense of belonging and to be accepted within a family or group, i.e. the need for emotional relationships such as friendship and for a supportive and communicative family. If these needs for love and belonging are not satisfied, people may suffer from loneliness, depression and social anxiety. Esteem needs are the fourth level in Maslow's hierarchy; the need to be respected, to have self-respect and to respect others. If these needs are not fulfilled, the result can be low self-esteem (Maslow, 1943; Huitt, 2004). Maslow initially described only one growth need – self-actualisation; later he differentiated the growth needs

of self-actualisation as cognitive, aesthetic, self-actualisation and self-transcendence (Huitt, 2004). However, Maslow's hierarchy of needs assumes a sense of priority for which there is little evidence. For example, some groups might value social relationships within the group more than their own physiological needs.



**Figure 2.2** Maslow's hierarchy of needs (Huitt, 2004).

Children's needs can be viewed as being related to their health or development or disability (Sheppard and Woodcock, 1999) and can be explained as a 'deficit state', meaning that a child 'in need' is suffering or will suffer some form of 'harm' if its needs are not fulfilled (Sheppard and Woodcock, 1999). The American Maternal and Child Health Bureau defines children with special health-care needs (CSHCN) as 'those who have or are at increased risk for a chronic physical, developmental, behavioural, or emotional condition and who also

require health and related services of a type or amount beyond that required by children generally' (McPherson et al., 1998, p. 138). This definition is employed in an Icelandic study of schoolchildren with special health-care needs (Iceland, Primary Health Care of the Capital Area, 2005) and is also suitable for the present study. Moreover, when considering young people's needs it is important to bear in mind the special needs of children since they are in a dynamic state of growth and development as individuals, and their early years are thus of great importance (Price, 1994). Furthermore, children are at their most dependent on the environment they are living in, and their psychological development can be affected by personal as well as family or social circumstances. Therefore, when their circumstances change their needs may also become different (Price, 1994).

#### **2.3.4. Key terms**

*Adolescent:* Most researchers have parsed adolescence into three developmental periods, entailing early adolescence (ages 10–13), middle adolescence (ages 14–17) and late adolescence (18 until the early 20s) (Smetana et al., 2006). The co-researcher in this study are aged from 11-16 years old and thus in their early and middle adolescence.

*ADHD:* Attention-Deficit/Hyperactivity Disorder (ADHD) 'is a clinically defined syndrome characterised by age inappropriate deficits in sustained attention, impulsivity and overactivity' (Baldursson et al., 2000, p.413).

*Children with special health- care needs (CSHCN):* 'those who have or are at increased risk for a chronic physical, developmental, behavioural, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally' (McPherson et al., 1998, p.138).

### **2.3.5. Summary**

In this chapter I have discussed the phenomenological literature on children and adolescents, as well as other perspectives in studies of young people with ADHD and the issue of needs. Key terms were introduced. The next chapter is concerned with the methodology I have chosen and the methods used in the study.

### **3. Research design: methodology and methods**

#### **3.1. Introduction**

The second chapter reviewed the literature related to the research question: What is the lived experience of ADHD from the perspective of adolescents with emphasis on their self-reported needs? In order to address this question I chose the interpretive-constructivist paradigm and my study is a phenomenological study within this paradigm. The Vancouver School of doing phenomenology guided me in the research process; it underpinned my arrangements and the measures I used to select a sample of participants, the data collection and data analysis, and my way of being with my co-researchers.

#### **3.2. Research paradigm and rationale**

The interpretivist-constructivist paradigm has grown, in the last few decades, out of social and nursing researchers' dissatisfaction with traditional science and its quantitative methods. Nurse researchers indicated that the positivist paradigm was inappropriate in studying human circumstances and experiences, as it reduces human beings to small quantitative units under investigation, rather than understanding the meanings and purposes that individuals construct around their experience (Chung and Nolan, 1994; Omery, 1983). It was argued that the social world could be known, even if incompletely and imperfectly, by going 'to the things' themselves (Cohen, 1987) and studying them in their natural context, not in artificial circumstances.

Constructivism's basic belief about reality is that it is relative, as multiple realities exist collectively in the form of local and specific mental constructions created by the persons or groups holding them (Annells, 1999). The constructions are not the 'truth' in any absolute sense, and they are always alterable and open to reinterpretation (Guba and Lincoln, 1998). Because of individuals' social situations and lived experiences, these constructed realities are different in their content and form, even though some of their elements can be shared by many individuals and even across cultures (Guba and Lincoln, 1998). I believe this basic principle of multiple constructed realities is appropriate in exploring the experiences of being a young person with ADHD. The young people in my study experience multiple realities collectively in their lives. They live in their different worlds of relationships and family traditions and they have different personalities, gifts and talents. All of these affect their lives, and how they create meanings out of events and phenomena through social interaction occurring in particular places and times. Being a young person with ADHD living in our western, Icelandic society is their lived experience that I wish to explore, emphasizing their self-reported needs. In addition, it is probable that they share some of their lived experience with other young people with ADHD in Iceland and also in other countries.

Within the interpretivist-constructivist paradigm it is thought that, in order to know the world, the researcher and the co-researcher need to be interactively and subjectively linked together as they co-create the findings. Therefore, what can be known – the findings – is always intertwined with the interaction between the researcher and the co-researcher (Guba and Lincoln, 1998). The aims of research in this paradigm are understanding and reconstruction in order to understand the 'complex world of lived experience from the point of view of those who live it' (Schwandt, 1998, p. 221). The researcher and co-researcher have their initial constructions, aiming towards some consensus, but are open to new



interpretations as their understanding improves through dialogue and by actively advocating for the competing constructions via a hermeneutic/dialectic process in order to find the most informed and sophisticated knowledge about the co-researcher's lived experience (Guba and Lincoln, 1998).

I believe the basic principles of the interpretive paradigm are consistent with my own values and beliefs, in nursing and in life. They are consistent with the holistic view I try to maintain vis-à-vis my clients, who are living in their multiple realities. I find it ethical and respectful to meet people, not least young people, on equal terms, in the hermeneutic dialogue, trying to understand their lives and together explore, interpret and construct the meaning of their lived situations.

### **3.3. Phenomenology**

Phenomenology grew out of the social sciences' critique of positivism inappropriately used to study human concerns, arguing that more than purely sense data (or 'observable behaviours') were acceptable data (Cohen, 1987). The phenomenological approach is concerned with the phenomena, intending to provide answers to important questions and deep human concerns (Cohen, 1987), adding new perspectives and broadening our knowledge of the human issues (Sadala and Adorno, 2002). Moreover, the phenomenological approach is compatible with nursing philosophy and nursing art in understanding individuals and their meanings and interactions with others and their environment (Lopez and Willis, 2004).

The purpose of phenomenology is to explore phenomena, the lived experience of people 'in their fullest breadth and depth' (Spiegelberg, 1976, p.2), and to describe people's

experiences in a way that is true to their lives (Anderson, 1991). Phenomenological studies begin by going ‘to the things’ themselves, in the world of lived experience, unblocked from theories or meanings to really see what is in the world (Spiegelberg, 1976; Cohen, 1987). The individuals are the trusted informants, giving their views and information about their everyday lived experience, studied in their natural context (Cohen, 1987).

### **3.4. Hermeneutic phenomenology**

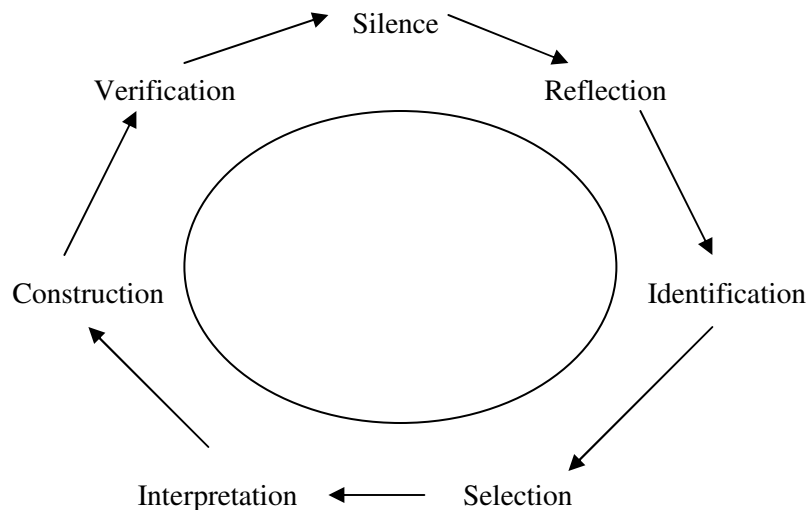
Interpretive/hermeneutic phenomenology is a philosophical tradition informed by Heidegger, Gadamer and Ricoeur (De Witt and Ploeg, 2006; Halldorsdottir, 2000). Research informed by interpretive phenomenology goes beyond mere description of core concepts and essences and seeks to reveal and convey deep insight and understanding of the hidden meanings of everyday life experiences (Lopez and Willis, 2004; Cohen and Omery, 1994; Ray, 1994). These meanings are not always obvious for the participants but can be gathered from their narratives by interpretation (Lopez and Willis, 2004). In my study I aim towards an increased understanding of the meanings in the young people’s lives. Gadamer (1986, p. 273) described understanding as a ‘fusion of horizons’. We all live within our own horizons, which encompass everything that can be seen from our point of view, and also what is beyond and invisible to us. I am in the world; my horizon is shaped by my background and history, my life and experiences. The children are also in the world; their horizons are shaped by their background and history, family circumstances and social backgrounds. It is through the hermeneutic dialogue that the horizons can be fused together into a common view of the subject matter. We have the possibility to move beyond the subjectivity of our private and direct experience into a world of common understanding (Cohen, 1987), and collectively analyse meanings or search for hidden messages (Koch, 1999).

In analysing transcripts from a research study, the interpretive researcher moves beyond what the text says ('explanation') to understanding what it talks about ('understanding') (Ricoeur, 1981), 'recognising the movement of the whole and realising the contribution of the parts' (the hermeneutic circle) (Koch, 1999, p.26), constructing and reconstructing, in order to find the most informed and sophisticated knowledge about the participants' lived experience. The meaning of the text does not only exist with its author, the research participant, nor is only one understanding, the author's, meaningful or correct (Ricoeur, 1981; Geanellos, 2000). Consequently, related to the pre-understandings of the researchers, the same text has many meanings, interpreted faithfully yet differently by the interpreters (Ricoeur, 1981; Geanellos, 2000).

'Bracketing' is a term frequently applied within phenomenological research; a process whereby the researcher holds all his preconceptions in abeyance, in order to get in touch with the experiences without relating them to previous knowledge and experience (Beech, 1999). However, according to the hermeneutic phenomenological approach it is impossible to separate the human being from the world, as the world and the person are an indissoluble whole; we are constructed by the world we live in and we construct it with our experiences and history (Koch, 1999). Thus, we always come to a situation or research with a story which is 'already with us in the world' and a value-oriented approach is unavoidable because of our pre-understandings and historical context (Koch, 1995, p.831). When researchers adopt the hermeneutic approach, therefore, instead of bracketing and setting aside their biases, they clarify and integrate them into the research findings (De Witt and Ploeg, 2006). However, in my opinion it is important for the interpretive researcher to have a high degree of self-knowledge. As a researcher I need to be aware of my preconceptions and prejudices, and must not be confused by my own history, feelings and beliefs, but rather be supported by them in constructing meanings of the world of young people with ADHD.

### 3.5. Vancouver School of doing phenomenology

This study was planned as a phenomenological study within the Vancouver School which is an interpretive-constructivist school of doing phenomenology. In the Vancouver School it is maintained that the world is made up of constructed meanings which affect how people experience and live their lives (Halldorsdottir, 2000). The research methodology is hermeneutic and dialectic, with the aim first and foremost to understand the experience of people in order to be able to coach them or guide them better, for example through difficult times in their lives (Halldorsdottir, 2000). Therefore, the Vancouver School is in harmony with nursing research in promoting the ‘common good’ and offers opportunities for nurses who want to understand the lived experience of their clients and increase the quality of the care they give them (Halldorsdottir, 2000).



**Figure 3.1** The process of doing phenomenology in the Vancouver School (Halldorsdottir, 2000, p.56).

1. Selecting dialogue partners (*the sample*).
2. First, there is silence (*before entering a dialogue*).
3. Participating in a dialogue (*data collection*).
4. Sharpened awareness of words (*data analysis*).
5. Beginning consideration of essences (*coding*).
6. Constructing the essential structure of the phenomenon for each case (*individual case constructions*).
7. Verifying the single case construction with the co-researcher.
8. Constructing the essential structure of the phenomenon from all the cases (*metasynthesis of all the different case constructions*).
9. Comparing the essential structure with the data.
10. Identifying the over-riding theme which describes the phenomenon (*interpreting the meaning of the phenomenon*).
11. Verifying the essential structure (*the findings*) with some research participants.
12. Writing up the findings.

**Table 3.1** The 12 basic steps of the Vancouver School (Halldorsdottir, 2000, p.57).

In the Vancouver School the research process is ‘indeed a process and not a linear phenomenon’ (Halldorsdottir, 2000, p.56), with seven basic stages of *silence, reflection, identification, selection, interpretation, construction and verification* (see Figure 3.1). Every one of the basic stages was entered into repeatedly throughout the 12 basic steps of the Vancouver School (see Table 3.1) that guided me in the research process.

### **3.6. Methods: Sampling, data collection and data analysis**

In this section I will discuss the methods used for sampling, data collection and data analysis related to the phenomenological methodology that underpinned the study.

### **3.7. Sampling**

In seeking richness of data the sample was purposefully selected, seeking individuals who had both typical and atypical experience of being an adolescent living with ADHD (Morse, 1991). The sample was selected according to the co-researchers' knowledge about the phenomenon (Morse, 1991). I searched for 'good' informants who were verbally developed and were willing to share their experiences with me (Morse, 1991). The participants needed to represent the population as well as possible (Halldorsdottir, 2000), consisting of both younger and older boys and girls, from the Reykjavík area as well as from other parts of the country.

According to Coyne (1998), young people want to 'tell their story', and when they are ready to do so the researcher will obtain credible data about what is meaningful to the young people. The physical and social environment of the dialogue is of great importance and can influence the nature of interaction between the child and the researcher as well as the outcome of the dialogue (Morison et al., 2000). Before the dialogue it is useful to reflect on the nature of the topic and what emotions it might bring out for the child to talk about it (Morison et al., 2000). Settings for the dialogues must be carefully chosen with the young people and their parents, to be where the young people feel most comfortable and relaxed (Miller, 2000), and where there is privacy and intimacy (Coyne, 1998). I was keen to talk with the young people privately, so they would feel able to express any concerns they had,

which they might feel unable to articulate in front of their parents (Miller, 2000; Coyne, 1998). However, it was acknowledged that this might be unacceptable to some parents or young people (Miller, 2000).

### **3.8. Data collection**

In the Vancouver School data are collected through true dialogues where the dialogue partners ‘feel free to speak and listen; feel listened to and heard; feel understood; and are empowered by the dialogue’ (Halldorsdottir, 2000, p. 60).

The researcher him/herself is the most important research instrument, as he/she is using him/herself to construct a deeper understanding of the phenomenon under investigation (Fleming et al., 2002). In my study it was important to pay special attention to the young people, as well as to the phenomenon of interest, and listen with more than the ears, applying all the senses (Omery, 1983). In the Vancouver School, the researcher and the co-researcher meet as dialogue partners; the initial distance and difference between them are acknowledged and ‘the dance of the dialogue begins’, as both of them wish to communicate and understand (Halldorsdottir, 1996).

### **3.9. Data analysis**

Although phenomenologists are sometimes unwilling to use specific steps in the data analysis process because of the risk that they will be handled as in natural science, in practice many researchers have worked out methods that can be followed systematically (Priest, 2002). In the Vancouver School processes of data collection, literature review and data analysis run simultaneously (see Figure 2.1) as the dialogues open up the phenomenon,

providing new themes and sub-themes from each case construction and then from the metasynthesis of all the different case constructions (see Table 3.2) (Halldorsdottir, 2000).

The final step in the research process is writing up the findings, where preferably all the co-researchers will have a voice. The researcher tells the stories of his/her co-researchers and the '[r]eaders take hold of this text and read their way into it, perhaps making it one of the stories they will tell about themselves' (Denzin, 1994, p.507).

### **3.10. Trustworthiness**

According to Kortesluoma et al. (2003), we as adults will never see the world through a child's eyes; we will see it through layers of knowledge and experience. We as interpretive researchers always come to research with a story that is 'already with us in the world' and a value-oriented approach is unavoidable because of our pre-understandings and historical context (Koch, 1995, p.831). The researcher is the 'research instrument' and therefore the validity depends to a great extent on the competence and personality of the researcher as well as his/her methodological skill, sensitivity and integrity (Halldorsdottir, 2000). Thus, it is important for the interpretive researcher to have a high degree of self-knowledge and to critically reflect on possible biases and blind spots and continually question the quality of his/her collection, analysis and presentation of the data (Halldorsdottir, 2000).

The findings of the study are qualitative data; constructions of the phenomena being studied. It is not a quantitative study with measurable data, intended to prove or predict something in the young people's lives. Lincoln and Guba (1985) maintain that how the researcher persuades his or her audiences is what is most important in relation to the trustworthiness of qualitative study. The trustworthiness of the study is dependent on whether the qualitative



data from the research would be immediately recognized by the young people having that experience as well as by other people (other researchers or readers) who have only read about it in the study (Halldorsdottir, 2007). Moreover, the data may sensitize the readers to some aspects of phenomena of which they were unaware before. Hopefully, health-care professionals, educational professionals, parents, siblings and the young people with ADHD will find some value in the data (see Halldorsdottir, 2007). However, only the future can tell us how ‘sound’, ‘convincing’ or ‘conclusive’ the findings are (Halldorsdottir, 2000).

### **3.11. Ethics in research with young people**

Research should only be performed on children if it cannot be performed on adults (Royal College of Paediatrics, Child Health: Ethics Advisory Committee, 2000), and in preparing my study I considered collecting data through interviews with adults about what it was like to be a child with ADHD. However, only the young people themselves can describe their feelings and views connected to their lived experiences. Also, it is the children’s right to express their views in matters affecting themselves (United Nations Convention on the Rights of the Child, 1989).

Consent is viewed as valid if the consent is given by someone competent to do so, if the person giving consent is adequately informed and the consent is given voluntarily (Beauchamp and Childress, 2001). The children’s competence to give informed consent varies according to their age and developmental stage. When the children cannot give consent, or are not allowed by law to do so, their parents or custodians must give consent on their behalf (Allmark, 2002).

In research with children and adolescents it is important to be aware of the adult-child as well as the nurse-child power differences, as the child or its parents may feel obliged to consent through respect, gratitude or fear (Bricher, 1999; Allmark, 2002). Moreover, it is important to make it clear to the young people and the parents that they can always withdraw from the study without any explanation or adverse effects on any service offered to them.

Confidentiality is a fundamental part of respecting and protecting the participants (Coyne, 1998), and in my experience adolescents are especially concerned with confidentiality, and need to be certain that their responses will not be shared with their parents (Faux et al., 1988; Allmark, 2002). However, in my research I was aware of the possibility that it might be necessary to violate confidentiality to protect the child, for example if issues of child abuse were revealed in the interview (Alderson and Morrow, 2004).

### **3.12. Summary**

In this chapter I have discussed the issues of the interpretivist-constructivist paradigm, phenomenology and the Vancouver School that underpinned my choices in selecting the sample, the data collection and analysis. In addition, the ethical issues involved in research with young people were explained. In the fourth chapter I will describe how phenomenology guided me in my research.

## **4. Data collection and analysis**

### **4.1. Introduction**

The third chapter was concerned with some of the issues of the interpretivist-constructivist paradigm, as my study is underpinned by the Vancouver School of doing phenomenology which is within that paradigm. In this chapter I will explain the issues of access, sampling, data gathering, data analysis, ethics and trustworthiness in my study.

### **4.2. Access and permission for data collection**

In December 2005 I asked for an informal meeting with the president and the secretary of the ‘Association’, to explain the study and to ask them to help me in recruiting participants for the study. They showed interest in the study and gave me permission to advertise for participants through the ‘Association’. Information about the study was sent by e-mail to the ‘Association’ (see Appendix I).

After the National Bioethics Committee (NBC) had approved the study (see Appendix II, III, IV, V), I sent the advertisement (see Appendix VI) in an e-mail to the ‘Association’ which forwarded it to the members on their mailing list. All their membership is in Iceland. The members are parents of young people with ADHD, and adults with ADHD. The advertisement was sent twice to the members on the Association’s mailing list. After the first advertisement (in March 2006), the parents of ten young people called or sent an e-mail asking for more information and showed some interest in the study. However, these were all parents of boys and some of the boys were diagnosed as having attention deficit without hyperactivity, and thus did not belong to the population selected for the study. Hence, only

three boys decided to participate in the study. Then the advertisement was sent out again to the members on the 'Association's' mailing list in April 2006, specifically asking for girls to participate in the study. Parents of four girls answered the advertisement; all participated in the study. Information about the study was sent to all parents who showed some interest in the study and they were asked to read it carefully with their children before they decided if they wanted to participate (see Appendix VII).

In September 2006 I realized that I needed more information for the research and decided to try to obtain some more participants. I telephoned the head of the Schools Section at the Centre for Child Health, and asked if they could send the advertisement by e-mail to all the school nurses in the country, asking especially for participation of boys aged from 14 to 16 years old. Parents of six boys answered the advertisement. However, only three boys belonged to the population selected for the study and decided to participate in the study.

Parents are important gate-keepers, and without their co-operation young people cannot be accessed (Faux et al., 1988). Therefore, I invited the parents to meet me without their children in order to learn more about the study (see Appendix VII). No parent took up this invitation. Nevertheless, I was contacted by 20 parents who showed interest in the study and asked for more information.

### **4.3. The population and the sample**

The population consisted of adolescents, aged from 11 to 16 years old in 2006, with ADHD, who were living in Iceland. I chose young people in this age group because adolescence is assumed to be a difficult time for young people with ADHD (Barkley, 1998), with additional problems in the family and at school. Moreover, adolescents aged 11–16 have

already been pupils at elementary school for five to ten years, and therefore I assumed that they might have some experiences to reflect on, which would give an insight into what it is like to be a young person with ADHD in elementary school. This would hopefully provide new information and understanding to support those who work with children and adolescents.

<b>Sex</b>	<b>Number</b>		<b>Domicile</b>	<b>Number</b>
Boy	6		The capital area	5
Girl	4		Outside the capital area	5
<b>Age</b>			<b>Family structure</b>	
11–12	4		Single-parent family	2
13–14	4		Two-parent family	7
15–16	2		Foster family	1

**Table 4.1** Characteristics of the young people.

The sample was purposefully selected and consisted of ten participants; six boys and four girls (see Table 4.1). All the participants had been diagnosed as having ADHD with its core symptoms and different comorbidity. The participants represented the population with regard to age range, and there were more boys than girls, which is typical for the population. Five of the young people were from the capital area and five from other parts of the country, which is typical for the population of Iceland as about half the country's inhabitants live in the capital area.

#### **4.4. Data collection**

The data collection took place from April to October 2006. The adolescents and their parents generally chose their own home for the dialogues; in the child's room if the family were at home, or in the living room, in which case the parents left the house. Four adolescents wished to meet me in my private setting. All the dialogues were private except one (a second dialogue with the young person in question) when we sat in the kitchen while the mother made dinner. I met eight of the young people once and two of them twice, resulting in a total of 12 dialogues. The duration of the dialogues varied from 14 to 81 minutes; most of the dialogues lasted about 25–40 minutes. Although children older than ten can be interviewed for an hour or more without difficulty (Faux et al., 1988), I felt it was important to ensure that I did not fatigue the young people, so I paused and stopped the interviews when necessary (see Miller, 2000).

The participants were approached with very broad questions (Halldorsdottir, 2000) to identify experiences significant to the adolescents, which we could then discuss in more depth (Halldorsdottir, 2000, p.61). I usually started the dialogue by explaining the purpose of the study and why I was interested in researching lived experiences of being a young

person with ADHD. I also explained that they could say anything they wished and start wherever they wanted. The following is a sample of the interview questions: ‘What is it like to be a boy/girl with ADHD?’ ‘What is most important for you as a kid with ADHD and what do you need most in life?’ ‘What have you experienced that is helpful and supportive, or unhelpful and unsupportive in your life situations?’ Most of the young people showed good verbal development and responded actively to the broad questions. However, broad questions proved unsuitable for some of the participants, especially for some of the younger ones. For instance, one of the boys (aged 12) said: ‘I like it better if you ask me direct questions’. In these instances it helped to ask ‘what usually happens?’ for questions about children with ADHD (Docherty and Sandelowski, 1999), i.e. to ask: ‘Kids with ADHD; how do you think they feel at school? What do you think might be most helpful for them?’ It was also important to use simple words and sentences and to make sure that the child understood the questions. Furthermore, it was vital to be sensitive to the young people’s non-verbal cues in the dialogues (see Greig and Taylor, 1999), such as facial expressions and body movements, and to follow up any openings in the dialogues where the child started to say something and then stopped because she/he did not have the words to express his/her feelings. However, children and adolescents may perceive the adult as a dominant authority figure and be anxious or shy during the interview (Coyne, 1998). Therefore, in the dialogues I felt the most important thing was to manage to reduce the adult-child power differences, in order to gain their interest and make them feel secure, by showing respect and being friendly and sensitive. Also, I felt it was very important to be open and receptive to the adolescents’s views and to allow them to express their feelings and experiences as best they could (Coyne, 1998), and to respond well to their answers and encourage them to continue to talk by praising them, for example by saying: ‘You have explained that incredibly well’ or ‘you have told me a lot that I didn’t know before, that was great’ (see Morison et al., 2000).

All the dialogues were audio-taped and transcribed word for word, except the first dialogue because the audiotape went wrong and there was nothing on the tape when I came home from the meeting with the adolescent. Therefore I had to transcribe the main topics of the first dialogue from memory.

#### **4.5. Data analysis**

As recommended in the Vancouver School I immersed myself in the data by listening carefully to the dialogues and by reading and rereading the transcripts attentively in order to get the sense of the lived experience of the young people.

Key statements and themes of key statements by the young people that had a special bearing on the phenomenon were identified. I tried to find the essence of what every one of the adolescents was saying, and then I constructed the essential structure of the phenomenon for each dialogue partner by taking all the different themes that had been constructed in each case, grouping them and building the analytical framework of the phenomenon in the way the young person had experienced it.

I then compared the different dialogues of the adolescents in order to find the ‘common threads’ (Halldorsdottir, 2000, p.64), as well as the differences in their stories. This was a metasynthesis of all the different case constructions in order to construct the essential structure of the phenomenon. The understanding of the lived experience of adolescents with ADHD is constructed firstly by understanding the individual cases and then by understanding them as a whole (Halldorsdottir, 2000).



The overriding theme describing the phenomenon of *being a young person in early and middle adolescence with ADHD with emphasis on their self-reported needs* was constructed as *‘the need to be accepted as you are’* since I found this to be a common element in all the dialogues, from the first dialogue to the last. Finally, I wrote up the findings as a multi-voiced text where everyone involved has a voice (see Halldorsdottir, 2000).

#### **4.6. Ethics**

The research was based on information about the health/disease history of participants, and therefore subject to approval from the National Bioethics Committee (NBC) and had to be reported to the Icelandic Data Protection Authority (see Appendix VIII). However, information about the adolescents’ medical diagnosis, symptoms and comorbidity was only gathered from what they themselves said. Approval was granted by the NBC in February 2006 (see Appendix V).

As requested by the NBC, I designed the information sheet and the advertisement taking into account the young people’s cognitive development and special needs, and also stating that declining to participate at any stage of the project would have no adverse effects on any service offered to the participants (see Appendix II, IV, V, VI, VII). In addition, a framework for the interviews was sent to the NBC (see Appendix III).

Prior to the first meeting I mailed the information sheet to the parents and asked them to read it with their adolescent. I emphasized that it was vital that the young person her/himself wished to participate in the study, as it would not be ethical to make the child participate merely because the parent was interested in the study. All the young people and their parents signed the informed consent (Appendix IX).

Exploring people's feelings and experiences may entail psychological effects, negative as well as positive (Allmark, 2002). I explained this risk to the adolescents and their parents and offered them the opportunity to meet with an expert who was not connected to the study (see Appendix VII). To my knowledge no young person made use of this opportunity.

Iceland has a small population; for this reason it is rare to be a child with ADHD, and this increases the risk of identification. Consequently, special arrangements were made in order to ensure confidentiality in the study, such as using pseudonyms and invented social situations.

#### **4.7. Trustworthiness – the rigour of the study**

The inherent methodological danger of the research is that what I see in the text may to some extent be the result of my own preconceptions about being a child with ADHD, and that I may ignore what I do not expect to see. Therefore, as recommended by the Vancouver School, I verified the 'case constructions' with the relevant young person. In the event I was unable to make contact with two of the co-researchers to verify their case constructions, but all the other eight young people verified their case constructions.

Throughout the research process I recorded in my reflective diary my thoughts and feelings related to the study and actively worked on being aware of my preconceptions and prejudices, trying not to be confused by my own history, feelings and beliefs, but rather to be supported by them in constructing meanings in the world of young people with ADHD. In order to validate the data, I compared the metasynthesis of all the different case constructions with the transcripts to see how it fitted. In addition, the final analytical

framework was presented to two of the young people in the study to see if they recognized their experience within the analytical description; both of them approved.

#### **4.8. Summary**

In this chapter I have described the data collection and data analysis of my research, guided by the Vancouver School. In the fifth chapter I will present the findings of the study.

## **5. Findings**

### **5.1. Introduction**

In the fourth chapter I explained the issues of access, sampling, data gathering, data analysis, ethics and trustworthiness in my study. In this chapter I will introduce the findings of the study. The findings were constructed from 12 dialogues with ten adolescents aged 11–16 years old as an answer to the research question: What is the lived experience of ADHD from the perspective of adolescents with emphasis on their self-reported needs? I begin with a phenomenological description and an overview of the findings, and then introduce the themes and sub-themes. Four main themes were constructed from the adolescents' accounts: firstly, their need for intimacy and closeness; secondly, their need for knowledge and understanding – not prejudice; thirdly, their need to be supported; and finally, their need for a positive self-image. The overriding theme describing the needs of the young people was constructed as *the need to be accepted as you are*.

### **5.2. A phenomenological description – an overview of the findings**

It is evident from the accounts that the young people's needs vary greatly from one person to the next and from one time to another. Some of the adolescents were able to look back and reflect on their lives when they were younger and to compare this with their lives today. The young people have a deep need and desire *to be accepted as they are*. They need to experience intimacy and closeness with their parents and custodians; to be listened to and heard, understood and approved. Some of the adolescents have a strong sense of being in a close and intimate relationship with their parents while others experience a lack of the

closeness they need and desire. The adolescents themselves acknowledge that it is not easy to have a child with ADHD. Some of them described how they are afraid that their behaviour might make their parents dislike them. The adolescents also need people to be knowledgeable about ADHD and not be prejudiced against them; to forgive them and not judge them.

Support at home from parents and elder brothers and sisters is important to the young people. Support from peers and pets is also of great importance. The adolescents need friends they can talk to about anything, who back them up when they get into trouble or feel bad. Many of the young people experience difficulties in their peer relationships. They tend to lose their friends because they say or do something that makes their friends stop wanting to be their friends. Some have experienced difficulties in making friends because people are prejudiced against them, whereas others have found it easy to make friends and enjoy good supportive friendships. A number of the young people have experienced bullying and teasing, in some cases over a period of several years, which made them feel sad and depressed.

Most of the adolescents express a great need to be supported at school. They need caring relationships; they need to feel cared for by teachers, by the school nurse and other school staff. Many of them experience school as the most difficult area of their lives. Their hyperactive behaviour – excitability, irritation and occasional aggression, coupled with lack of concentration and educational difficulties – negatively affects their school life. Some of them do not attend school at times because they are afraid they will be bullied or because they have not managed to do their homework as it takes them much longer than their peers. They need their teachers to understand them. Some of the young people reported a positive experience of support from school staff, although one young person described how her

teachers bullied her and her friend who also had ADHD. Few of the young people had experienced help or support from the school nurse. However, for those who had, her help and support were of great importance and one young person felt she was the only person who understood her. The adolescents felt that life had been more difficult when they were younger and did not understand what was wrong or know how to handle themselves. They explained that it is important to get help when it is needed – at an early age if necessary. Those who had been helped at an early age found it an advantage when they were older.

The young people also expressed a great need for a positive self-image. They need self-knowledge and knowledge about ADHD, and in addition need to identify their own strengths and build on them. Finally, they expressed the need to be optimistic and to have faith and hope.

### 5.3. The needs of young people with ADHD in early and middle adolescence – from their own perspective

<i>The need to be accepted as you are</i>			
5.3.1. <b>The need for intimacy and closeness</b>	5.3.2. <b>The need for knowledge and understanding – not prejudice</b>	5.3.3. <b>The need to be supported</b>	5.3.4. <b>The need for a positive self-image</b>
The need for intimacy and closeness with parents and custodians	The need to be forgiven – not judged	The need to be supported at home	The need for self-knowledge
		The need for emotional support from peers and pets	The need to identify their own strengths and build on them
		The need to be supported at school	The need for optimism, hope and faith

**Table 5.1** Self-reported needs of adolescents with ADHD.

The overriding theme describing the needs of the adolescents with ADHD was constructed as *the need to be accepted as you are*. The young people need the environment – their parents and custodians, brothers and sisters, peers and teachers – *to accept them as they are*. Moreover, they need to accept themselves and to strengthen their self-image. ‘You just are what you are and you don’t need to be anything else’ (Carl, A<sup>1</sup>, p.13). Ben explained:

Kids with ADHD, they just have to be themselves, they could never go to a wedding reception ...<sup>2</sup> and not say a word. The kids would either be talking the whole time or else saying the odd word. ... Of course you realize that it works out by far the best to be yourself (A, pp.3, 9).

### **5.3.1. The need for intimacy and closeness**

The adolescents expressed a great need for intimacy and closeness with their nearest relatives, especially their parents and custodians.

#### **5.3.1.1. The need for intimacy and closeness with parents and custodians**

The adolescents expressed how they need their parents to hear them, talk to them and try to understand: ‘It’s better [to talk together], yes, about everything that’s happening, that’s annoying you, and that sort of thing (Nicole, A, p.11).

Some of the young people have a strong sense of being in a close and intimate relationship with their parents while others experience a lack of the closeness they need and desire. Ben explained how it helped to be close to his mother when he was younger:

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<sup>1</sup>A indicates the first interview.

<sup>2</sup>Three dots indicate that material has been omitted from the account.



Having time together with my mum ... and just asking to be allowed to cuddle up in bed with my mum and talk about what had happened during the day and things like that, it often helps a lot ... I did that often, for example, when I was younger, just got into bed and talked and then maybe I'd fall asleep half an hour later ... instead of taking it out on mum I'd just always get into bed and we'd stay quiet for around ten minutes and then mum would maybe ask me: "Well, what did you do at school today?" And then maybe you'd forget all the bad things that happened at school ... I always used to do that. I think I stopped when I was 12 or something (A,pp.13–14).

Some of the adolescents described how they can be irritated and distressed, at times for no reason. Nicole described this experience and reflected on how it often affected her relationship with her mother:

I often get horribly irritated ... and then I just tell mum I'm irritated ... and that she shouldn't talk to me at all because ... otherwise I'll just get told off ... or something ... if I say anything at all ... maybe I tell her something ... about what happened at school ... and she misunderstands ... I get so irritated ... then I start arguing with her ... trying to make her understand ... and I feel she never understands me ... but ... actually she does understand (A,p.3).

Ben explained how important it is to be approved of and accepted by parents when you are 'different':

Like that Sugababes song, have you heard the one: "Ugly"? ... The girl sings that she was so ugly and different from all the other kids ... then she says in the lyrics that she asked her mum and dad what was wrong with her, and her mum and dad just told her she was beautiful and that she was ... cleverer than the kids in her class.

She says in the lyrics too that everything went better after that, which is quite right (A,pp.21–22).

Some of the young people had divorced parents and were living with their mother or with their mother and stepfather. Ben and Rose explained how it hurts not to have contact with their father. Ben also described how difficult it is for ‘a little boy with ADHD’ when his parents are divorcing:

If you’re ... a little boy ... and your mum and dad are getting divorced, it can be terribly difficult. ... Like I had ADHD, of course I was much younger and naturally I didn’t know what was happening and I didn’t take much notice of things until I knew that dad had just stopped coming home or that he didn’t live with us any more or something like that. And ... then it began to, you know, really hurt. But then I started going to see him, so after that it was OK (A,p.19).

Rose lives with her mother and stepfather. Her parents separated when she was very young. She explained that it was difficult when her parents were arguing and she was caught in the middle. She felt that what she needed most was more closeness and more time with her parents:

I don’t really spend any time with my mum or dad ... the only person I spend much time with is myself [silence]. So my family, they let me in, but even so it’s like they don’t want a whole lot to do with me. ... I’ve stopped being in touch with dad’s family. If I didn’t ring my dad from time to time, I would probably stop having any contact with them at all. ... When we moved to “Rivertown” things began to get better between me and mum at last because we always went at lunchtime ... and had something to eat. Actually, what I find helps me most is getting to spend time with my mum and dad, nothing else (A,pp.3, 10, 11, 22).

Ben and Nicole described how children with ADHD are afraid that their behaviour might make their parents dislike them: 'I always felt bad, I felt as if he [my father], you know, couldn't stand me or something' (Nicole, A,p.13). Ben explained:

Parents don't know that their children are afraid of talking about it and of being despised. ... Lots of people probably think your parents despise you for the things you do (A,p.21).

Some of them described how it is not always easy for parents and significant others to have a family member with ADHD. Annie explained:

Some people find it terribly difficult [to have child with ADHD] and [there are] lots of parents who just can't cope with it ... some kids don't get any help, and of course that's much harder (A,p.9).

### **5.3.2. The need for knowledge and understanding – not prejudice**

Many of the adolescents feel that people know little about ADHD and are prejudiced against them. They have also experienced bullying and teasing because of their ADHD. Michael said: 'It certainly never helps to be prejudiced about it. Of course it's probably very bad, like with teachers and so on, and relatives, they should just learn more about it. ... Just try to get more information about what it involves' (A,pp.10–11).

Annie experienced a great deal of prejudice, teasing and bullying at school when she was younger:

People, you see, they don't know what they're saying. ... They just [think] ... you're crazy because you're like that. Some sort of prejudice like that. And also: "Oh her, because she's so hyperactive I'm never going to talk to her, because she

might be a bit mental,” and things like that. ... Of course there’s nothing wrong with those people and [it’s] all right to make friends with them ... If I had made a really good friend when I was there at that time, we could just as well be friends today because there was nothing wrong with me. ... I’ve just changed and got better and so on, which is why I think it’s so sad that, that people make so few friends ... because of something like that: ... “Oh, she’s probably totally, totally different or something, that girl has to take drugs ... she might be dangerous” (A,p.12).

#### **5.3.2.1. The need to be forgiven – not judged**

Some of the young people mentioned how their irritability and difficult behaviour have affected the people around them, and how they need to be forgiven – not judged.

Rose and Nicole explained:

If they’re really going to understand us they need to be able to see through our eyes. ... [It’s] just no good judging us ... for example, you might see someone lose their temper in the street, but you shouldn’t ... think they’re a lunatic. It could be that something’s happened. It could be a person who’s got the same problems as me (Rose, A,p.25). The people around you, or your teacher, or something, they have to learn how to forgive you. Because you can do something just, you know, just suddenly start screaming or just say some nasty things about someone or something (Nicole, A,p.15).

#### **5.3.3. The need to be supported**

All the adolescents expressed a need to be supported. They need to be supported at home by parents and elder brothers and sisters. They also need emotional support from friends and

schoolmates, and some had pets that gave emotional support. They experience school as difficult and need to be supported there by the school staff:

I think people just ought to know, everyone ought to know ... doctors and everyone, that if young people have to take medicine then they can't just put the medicine on the table every morning and make them take it. ... Everyone needs support ... otherwise it doesn't work (Annie, A,p.18).

#### **5.3.3.1. The need to be supported at home**

'I could never have done this without my mum and dad. They gave me a huge amount of support.' (Annie, A,p.2). All the young people explained the importance of support and help from their parents. Their parents support them emotionally by talking to them and encouraging them, and by coming to school when something has gone wrong or by helping them discover their strengths, e.g. in different sporting activities. Some of the adolescents have a parent with ADHD who has their own lived experience which helps them to understand and support their adolescent. Ben said:

Mum ... if I tell her for example about something that happened at school or that I'm feeling bad or something like that, then of course she knows the answer. Because ... she's hyperactive herself and probably went through all this herself in her teens, or at the age she is now, at work or something. Of course she's going through the same thing as me and we can talk about it better together. If my mum wasn't hyperactive, I don't think we'd ever have talked together about hyperactivity ... she sometimes sits down with me and I talk to her about ADHD and she talks to me about ADHD and she gives me advice and so on. Things have just turned out like that and it has worked out really well (A,pp.3, 6-7).

Three of the young people explained that they had close relationships with their elder brother or sister who gave them emotional support by talking to them and encouraging them when they were feeling bad or something was going wrong. All the elder brothers and sisters of these young people were adults in their twenties and most of them had left home and lived by themselves. Tim explained how he was once feeling bad because his teacher at school talked down to him and did not understand his difficulties, so he called his big sister from school and she came and talked to the teacher. John used to call his big brother when he was feeling bad. Annie explained how her big sister knows what to do when she and her sister, who also has ADHD, are feeling bad:

My sister ... I think she's ... the best person I have, to talk to and that sort of thing ... she does everything so calmly, she does everything so well. ... She's learnt over the years how to do it. ... So that whenever ... we're feeling bad, we're sulking or something like that, she always comes and talks to us and it gets better at once (A,pp.19–20).

### **5.3.3.2. Emotional support from peers and pets**

All the young people described how important it is for them to have supportive friends.

'When someone is having problems it is good to have friends' (Beth, A,p.2). 'You can talk about anything with your friends; they really ... kind of help you through it' (Nicole, A,p.14). 'It's really good to have a friend who can always back you up if you get into some kind of trouble or feel bad or something' (Ben, A,p.15).

Nevertheless, many of the young people experience difficulties with friends and schoolmates. This was illustrated by Rose: 'I went to "Greentown" and I had one year left at

elementary school; it was a bit difficult for me to make friends. I only just managed to survive that' (A,p.5). Nicole said:

You can get so irritated sometimes, and suddenly start going on at your friends or something, for no reason. Then you say 'sorry' or something, but they won't listen to you ... Sometimes I feel ... I'm just not meant to have any friends or something, because all my relationships with friends, they just, you know, go wrong or something. ... I obviously do something ... that makes my friends just stop being my friends, just all of a sudden (A,p.4, 13).

Some of the young people experienced the sense of being different and alone. It can be hard to feel different, and their fear of being teased or rejected makes some of them withdraw from other people: '[You] think ... you can never make friends or anything' (Carl, A,p.12). This affects their self-esteem: 'I thought it was just me who was different, I didn't dare talk to anyone because I thought they'd just make fun of me and that sort of thing; because I was different' (Ben, A,p.7).

It isn't easy to make friends, I can tell you that. I've been through all that myself. ... You yourself think other people, you know, look at you differently. ... If I saw some kids down at the shop and I wanted to join them, I don't know if they're kids who are just like me and were alone before, and then you can either ask whether they'll come and do something or just find some other kids. Only, if you don't dare, then just go and find the next lot (Ben, A,pp.16–17).

However, as Ben and Carl explained, it is important to have the courage to ask instead of waiting for someone to be your friend: 'Like I waited for years and years and years, nothing happened, you see; it's much better to ask instead of waiting' (Ben, A,p.19).

Nicole, Rose and Annie had all experienced times when they were bullied, teased and disliked by schoolmates and teachers. They explained how it made them feel sad and depressed: 'I was always crying and used to come home from school in tears' (Annie, A,p.8). Nicole expressed how she felt when her schoolmates were teasing her:

I felt terrible when he was saying that because everyone was sort of making fun of me and things. You know, all my life I've just had to live with it, everyone is just ... saying I'm a phenomenon. I'm small and, far too small, and things like that. ... At that time I felt as if I was a nobody or something. Just [felt] that I was nothing. Yes, it happens terribly often ... that I cry (A,p.9).

Some of the young people have very good friends who they can talk to about their difficulties and who they spend a lot of time with, doing 'all sorts of things'. John explained the importance of his friends and elder brother:

I've got very loyal friends. ... If I'm in trouble I can ring them, talk to them and so on, lots of girlfriends too. ... I've also got a very loyal and kind big brother who I can always rely on. If I'm in some sort of trouble I can ring him and so on ... which is great ... I sometimes just ring my friends or girlfriends ... just to talk about how the day's been ... I find it so helpful. Also I just go on MSN. ... I just find it good to be able to talk to someone and just to have someone there who you can trust (A,pp.6-7).

The young people explained that it is important to tell their friends about their ADHD. If their friends know about their ADHD they can inform them if their behaviour is irritating and help them to relax: 'You tell them that you've got it and if they don't know what it is then you can explain to them. Then they understand better why you're like that and then they understand your personality better; it can help you an awful lot in life' (Rose, A,p.29).



On the other hand, some of them were afraid to tell their schoolmates in case they started bullying them, and emphasized the importance of telling a few good friends whom they knew they could trust.

Some of the young people described how they received emotional support from pets during difficult times. Rose said:

The only living creatures I could really trust and tell everything I wanted to tell, just like to my mum or something, that's animals. Because they can't hurt me ... [My cat] was actually the only animal that really understood me properly, when I felt bad he came to me and comforted me. ... He was always with me really ... that was really the [only] person I could ever trust' (A,p.8–9).

### 5.3.3.3. The need for support at school

The need for support at school		
The need for caring teachers	The need for a caring school nurse	The need for support and help when it is needed – at an early age

**Table 5.2**      The need for support at school.

Most of the young people expressed a great need for support at school. They described needing support and help with their educational difficulties as well as with their emotional and relationship problems; and that they should receive help when it is needed – at an early age. They expressed needing caring relationships; the need to feel cared for by their teacher, by their school nurse and other school staff.

All the young people had experienced difficulties at school, whether educational, behavioural or in relationships. Their behaviour can be difficult and at times disruptive in the classroom. They explained to me how they need to ‘be constantly moving’, ‘always talking and talking loudly’ and find it hard ‘to sit still’. Also, some of the young people expressed how they became agitated and easily hurt and upset: ‘when someone said something to me I took it, not exactly too seriously, but I got really upset ... and either attack[ed] the person ... or misbehaved in some way’ (Ben, A,p.4). ‘Maybe it wouldn’t hurt a normal person but ... we take some things badly’ (Annie, A,p.10). Ben described his behaviour at school before he found out he had ADHD:

All those years at my old school when I didn’t know I was hyperactive ... then naturally everyone got fed up with me straight away because I was so incredibly active and hyper and that sort of thing, always moving and answering back ... I often got into trouble and things like that but then, if you talked to someone it calmed you down a lot. If you told someone what was happening. But then time just passed and it carried on until mum had me tested ... But since I started on the drugs, things have just sort of improved (A,pp.1, 3).

Many of the young people also find it difficult to study and concentrate; it takes them much longer to do their homework than other young people, and some never do any homework at all. They also have a tendency to forget things. Some days their feelings about school are so

negative that they do not attend because they have not been able to complete their homework and feel ‘a terrible dread of going to school’ or are ‘afraid that someone will tease’ them. Several of them find theoretical studies boring and unsuited to them, whereas they find vocational studies and art easy and more enjoyable. Although some have ‘an above-average IQ’, this does not necessarily help them do their schoolwork, nor does it show up in test results.

#### **5.3.3.3.1. The need for caring teachers**

Some adolescents described how their teacher understood and supported them, for example by taking notice of their special needs, such as listening to music on an iPod or MP3 player while studying: ‘then I don’t need to be moving around and that sort of thing, as long as I know I’m listening to music and can study’ (Ben, A,p.8). One young person explained how a caring relationship with his art teacher was important for him. The fact that his teacher liked him as a person had a positive effect on his self-esteem and the art work he produced in his class.

Nicole described how her teacher listened to her and tried to understand her when she was irritated and how this calmed her and made her feel better:

She was terribly kind ... but she was terribly strict all the same ... she listened to you, she tried to understand you. That was the best thing, that’s really ... what’s needed, just understanding, just to listen, just to be like that, quietly, just listen and understand. ... If anyone starts, like her, starts talking to me like that, calming me down and listening to me or something, then it just goes away. ... And I just become sort of calm. ... I just have to talk about it or something. ... Then you feel much better somehow. ... You stop being irritated (A,pp.11–12).

In contrast, some adolescents felt their teachers came down hard on them and did not understand them. Annie said:

Our teacher who took our class in the seventh grade didn't know what she was doing. She knew [that I had ADHD] but it seemed like she didn't know what it was. It had obviously not been explained to her. She told me off and the boy ... who's also like this, so unbelievably often and we felt incredibly bad. And one day we didn't attend school for a week because the teachers were almost bullying us. It was always us, and we found it incredibly hard. While all the other kids who were doing it – there couldn't be anything wrong with them, because they maybe made less noise or maybe did something not quite as [bad]. But it was always us two who were picked on and told off. Oh, I don't know how often ... But that teacher didn't know what she was doing. [She] didn't know what was wrong. And it was always just us two, because maybe we made a bit more noise or something. And then we'd say: "But the others, what about the others?" "No, it was you two, it was you two", the answer was always something like that. And, you know, perhaps [it was] something we couldn't help (A,pp.13–14).

#### **5.3.3.3.2. The need for a caring school nurse**

Few of the young people mentioned the school nurse as a source of help and support. However, two youngsters who had suffered a great deal at school from bullying and other problems explained how 'incredibly much' the school nurse helped them. Annie described her caring school nurse:

I think the only person I talked to about this was the nurse at school, Betty, because she helped me so incredibly much ... I could always tell her how I felt and she

always asked every day. ... She was very understanding ... she always understood us, me and one of my friends, both diagnosed [with ADHD]. And we always had to go along together to take medicine or something. Sometimes I was teased so much at school, I felt unbelievably bad, so I was always with her, my nurse. I learnt very little ... in the second or third year. And she decided to have a special room with the nurses that she arranged for me and him. ... And she put a sofa in it and all sorts of things like that which we could use ... for us ... and of course we felt a bit better because we could go there. We were always welcome; there was no one who could stop us or anything (A,pp.1–2, 16).

#### **5.3.3.3.3. Support and help when it is needed – at an early age**

It was noticeable from the dialogues that the adolescents had experienced ‘far more’ problems when they were younger. Some of them explained that it was more difficult to cope with ADHD when they were younger because they lacked an understanding of their own feelings and behaviour – they did not have the self-knowledge they had ‘today’ – and also because they did not have the knowledge they needed about ADHD. Some of the young people had experienced bullying for years. They described how important it is to receive help when it is needed, at an early age: ‘When people get teased a lot in childhood ... I think it can have a really big effect on you when you’re older’ (Annie, A,p.11). Rose didn’t receive enough help when she needed it most. She was bullied for four to five years at school, from when she was eight until she was 12–13 years old. She said:

Try to accept help as much as possible while you’re young ... it helps. It’ll go on helping you a great deal in life. ... I didn’t get enough help when I was young so I have great difficulty accepting help now. But if you get help when you’re young you find it easier to accept help when you’re older ... [If] I had received help when I

needed it most ... that's what would have helped me and that's what would have helped me today (A,pp.17–18, 26).

#### **5.3.4. The need for a positive self-image**

It is evident from their accounts that the young people have a great need for a positive self-image. As already explained, their self-image has been attacked in many ways due to problems at school and difficult relationships with friends and family. They need self-knowledge and knowledge about ADHD, and also need to identify their own strengths and build on them. Furthermore, they need to be optimistic and to have faith and hope. Ben said:

Kids who have ADHD, they must have some sort of image of themselves and there are probably lots who don't have a negative image of themselves. [Then there are] probably lots who think they're ugly and different from other people and stupid and so on ... I know that lots of kids, they don't dare to talk to their mum or dad or anyone else. ... And nothing will come of, you know, their future because they haven't actually been given any information about how it – how this illness can be an advantage in lots of ways (A,p.7, 22).

##### **5.3.4.1. The need for self-knowledge**

Some of the young people had never heard of ADHD before being diagnosed, and described how important it was for them to know 'what was wrong ... what was really wrong with me ... I was actually really keen to know what it was' (Ben, A,p.21). Nicole knew something was wrong but not what it was: 'I always thought I was disabled, and I've felt terribly unhappy because of this' (A,pp.8–9). Many of the young people explained how they

experienced a change for the better in their lives once they knew they had ADHD and learned about the condition. Michael and Ben said:

I'd just never heard of it, [not] even heard it mentioned ... well, maybe something but of course I didn't think about it ... didn't think it could have anything to do with me. ... When I found out it seemed obvious to me. ... I thought it made perfect sense; a solution to all my problems (Michael, A,pp.1–2). Of course it's obvious; the more you know about something the more you can do. For example, you can't apply to be a pilot unless you know something about flying; it's just exactly the same. You naturally become much better informed and you know what you should do if you know about the illness. ... Since I found out [what was really wrong with me] everything has gone well for me and I know how to react if I do something wrong (Ben, A,pp.7–8, 21).

Some of the young people explained how their self-knowledge helps them to handle themselves better. Annie explained that when she was younger she did not understand what was wrong and responded badly when people were trying to help her:

I'm much better at trying to learn [how to handle] myself and help myself because now I can also understand what's wrong. ... I find it much easier to understand what's going on today and I try ... if someone said to me something like: "Annie, you just have to calm down," of course I'd just go: "Oh, yes, I must be careful," but when I was younger ... [it was] just: "What's the matter with you, why?" You know, I think it's much more like this. I'm better at understanding today than when I was younger (A,p.11).

One of the youngsters destroys things when she is feeling angry or irritated. She described how increased knowledge helps her to control herself:

Of course it helps me a lot to know that I have destructive tendencies. Then I know that I shouldn't go and take it out on the walls or something. Instead, take a pillow and beat it ... or shriek into the pillow so you won't disturb the people around you. Then you feel relieved. ... It's actually really good to know that you have these symptoms. ... So it helps me a lot to know. Then ... I can try to stop myself and sit down in order to relax a bit more (A,pp.27–28).

#### **5.3.4.2. The need to identify one's own strengths and build on them**

From the accounts it is evident how important it is for young people with ADHD to identify their own strengths and interests, and to build on them. Many of the adolescents described a sense of being creative and having lots of good ideas: 'lots of ideas ... sometimes very good ones' (Michael, A,p.12), 'but sometimes it happens that I can only remember one of them ... people with ADHD are often the ones who have the best [ideas] and often come up with all the ideas and do everything' (Ben, A,pp.10, 12). Ben explained how he managed to relate his schoolwork to 'word games or Sudoku or something ... then it started getting more and more fun; I managed to concentrate better, so it was easier to learn' (A,p.6). He also described how he makes use of his creativity in his written work and exams at school:

You get the idea so quickly and ... can write about anything at all because it's so easy for you. You get the idea so quickly – and about lots of things – and it's a bit over the top ... then I remember the next idea and then the next and the next and the next, until maybe you've come up with a really good story. ... And it can be good too that if you're revising for an exam, which I know lots of people don't do or can't be bothered to do, but if you revise for it and enjoy revising, it goes into your brain in no time at all and when you go into the exam it comes right back: "Yes, it could



be this, this or this”, then you just use a process of elimination and you’ve done the exam, with top marks and all (A,pp.12–13).

As already explained several young people felt theoretical studies were boring and unsuited to them, whereas vocational studies and art were easy and fun. Some of them described how ‘cooking’, ‘baking’ ‘drawing’ and woodwork’ made them feel good and happy: Rose said: ‘When I’m cooking and that sort of thing, and baking ... then I feel good, I’m happy, I don’t suffer from depression or attention deficit, it’s like that in woodwork too’ (A,p.4). This was explained by Michael as follows:

I just feel, like with studies and so on, I find theoretical studies dead boring and I’m much better at practical things, work and all that kind of thing. [I’m] very good at working ... I find it very easy to learn all sorts of practical things. ... [Practical things] somehow seem to suit me much better. It’s really good to find ... a release for some of your energy ... playing the drums is a very good release. It’s so cool, making music and playing an instrument, so cool, whether it’s because it gives you a release or not (A,pp.7–8, 11–12).

Ben described how he managed to find out what sports suited him:

I’d just tried out all the sports there are. I tried football, basketball, I tried badminton and athletics. ... Then just gymnastics, and gymnastics went so well ... that I did everything myself, I just did it for myself and not for my team. ... And I’ve done really well. ... But, like ADHD, you’re ... doing it for yourself, so you don’t always have to be worried about messing up and being told off for it (A,p.11).

Some of the young people identified the sense of not being shy when they meet strangers as one of their strengths: ‘I could easily just walk up and start talking’ (John, A,p.3). They also

explained how it can be an advantage to have ADHD and be ‘a bit hyper and ready for anything over the top’, for example for an actor who acts in thrillers.

Finally, Annie illustrated how living with ADHD has made her a more understanding and helpful person: ‘So that maybe we can help other people too. So sometimes it’s an advantage’ (A,p.18).

#### **5.3.4.3. The need for optimism, hope and faith**

The young people reported experiencing a need for optimism, hope and faith. They reported the need to accept their illness and have hope for the future and faith in themselves and other people. As already explained, some of the youngsters have experienced problems such as bullying or teasing for several years. Also, some have experienced feelings of being different and alone. This affects their ability to trust others and to be optimistic and hopeful. Rose explained:

I find it very difficult to trust people because of the bullying I experienced. ... Also because of this thing I have. In fact I’m often terribly negative. I just look on the black side, can’t see the positive side. ... My life’s just, been like a hell or something, at times’ (A,pp.3, 4, 11).

Some of the young people expressed their need for optimism and faith. Michael has a positive self-image, describing himself as ‘quite lucky’. He has even kept the same good friends since he was at playschool. He expressed his views about what can be helpful for young people with ADHD:

Not to be shy about admitting what’s the matter ... This illness ... or whatever you should call it; you just have to accept it and deal with it. That’s the only way to get

any sort of result, I think. ... Just try to get support and help from your parents and just accept it with an open mind (A,pp.5, 11).

In contrast, one of the adolescents experienced little hope for the future. She is worried about starting college because she knows she has educational difficulties and will need some help. She is also afraid that she might experience 'a bit of bullying'. Moreover, she fears the future; having to leave home and take care of herself: 'I see no future for myself. I just see emptiness' (A,p.14). Sometimes she has a feeling that there is no hope:

I find it very strange to be alive sometimes. It's happened – when I was nine years old I started to want to die. I was just fed up with life and I just wanted not to live any longer. ... Ever since I was nine years old I've been thinking like that. I still think like that from time to time now. ... The reason I'm talking about this is because I want to be able to help others. That's one of the few things I can actually do ... but I don't get to do [it] often enough [silence]. So it's actually one of the reasons why I'm talking about all this. That's the reason that I wanted to take part [in the study] (A,pp.2, 30).

## **5.4. Summary**

In this chapter the findings of the study were presented. Four main themes were constructed from the young people's accounts: the need for intimacy and closeness; the need for knowledge and understanding – not prejudice; the need to be supported and the need for a positive self-image. The overriding theme was constructed as *the need to be accepted as you are*. In chapter six the findings will be discussed and related to the relevant literature.

## **6. Discussion**

### **6.1. Introduction**

In chapter five the findings of this study were presented. The purpose of the study was to explore the lived experiences of adolescents living with ADHD, with emphasis on their self-reported needs. The overriding need was found to be *the need to be accepted as you are*. In addition, the themes were found to be interrelated. In this chapter I will discuss the findings and relate them to the relevant literature. As already explained, the perspectives of young people with ADHD constitute a particular gap in existing knowledge and I was not able to find any study in which the needs of young people with ADHD were explored from their own perspective. However, Lightfoot et al.'s (1999) qualitative research on ill and disabled young people was found to support many of the findings of the present study. Their sample included pupils with a chronic illness or physical disability that was judged to have an impact on school life. However, without research into the perspective of young people with ADHD, services are unlikely to be adapted to their needs, as the views of parents or teachers do not necessarily represent those of children (Tackett et al., 1990). The present study is bound by constraints of time, place and the circumstances of the young people and cannot, therefore, be generalized to a wider population.

### **6.2. The need to be accepted as you are**

The main finding of the study is that adolescents with ADHD *need to be accepted as they are*. They need to be themselves and to be accepted as they are by people in their environment; family, friends, teachers and others. In reviewing the literature I did not find any studies that explored *the need to be accepted as you are* of young people with ADHD.

Yet in the present study this need was constructed as being very deep and strong. Furthermore, and of great importance, they need to accept themselves and to strengthen their self-image, as the present study found that the young people's self-image had been attacked in many ways due to their problems at school and difficult relationships with friends and family. The psychologist Harter (1999) explains how a discrepancy between the adolescent's perceived competence and ideal self-images or aspirations is linked to his or her self-worth. Thus, adolescents who acknowledge that they lack competence or adequacy in domains for which they have aspirations of success show relatively low self-worth (Harter, 1999). In Dumas and Pelletier's (1999) study it was found that pre-adolescents with ADHD have lower perceptions of self-worth than their non-ADHD peers, specifically in the areas of scholastic competence, social acceptance and behavioural conduct. Hence, the two dimensions of self-perception with which hyperactive children did not have any problems were athletic competence and physical appearance (Dumas and Pelletier, 1999).

In the present study the need to be supported was found to be one of the main themes: the need to be supported at home, by parents and significant others; the need to be supported at school by teachers, the school nurse and other school staff, and the need for emotional support from peers and pets. Harter (1999) explains how support, particularly in the form of approval and validation for oneself as a person, has a clear impact on the self-evaluations of children and adolescents. In addition, parental support is particularly important throughout the period of childhood and adolescence, although peer support becomes increasingly important to self-worth as one moves into adolescence (Harter, 1999). Support from special adults like teachers or others in their environment may, for some adolescents, either enhance the effects of existing support from parents or compensate for the lack of parental support (Harter, 1999). Moreover, in Maslow's theory of the hierarchy of human needs the need for belongingness and love and for acceptance within a family or group is one of the human

basic needs. If these needs are not satisfied, people may suffer from loneliness, depression and social anxiety (Maslow, 1943).

In the present study the young people reported how they experienced a need for optimism, hope and faith. They reported needing to accept their illness and have hope for the future and faith in themselves and other people. Some of the youngsters had experienced problems such as bullying or teasing for several years. Furthermore, some had experienced feelings of being different and alone, and some reported how they went through periods when they were always crying and feeling depressed. Harter (1999) describes how depressive reactions, including depressed affect and hopelessness, are mostly related to low self-worth. Also, Harter (1999) determines that these depressive reactions are highly predictive of suicidal ideation. However, Harter also states that although research shows that the correlation between self-worth and depressed affect is high, it is impossible through causal modelling techniques to determine the directionality of effects, that is, which precedes which.

### **6.3. The need for intimacy and closeness with parents**

The young people interviewed for this study were in early and middle adolescence. Adolescence is a period of transition in which children become adults (Gleitman et al., 2004). Young people need to develop their personal self through their interpersonal relationships with their parents and significant others. They need to individuate from their parents while at the same time remaining psychologically connected to the family; achieve autonomy while maintaining a positive relationship with their parents (Harter, 1999). However, relationships are one of the major areas of difficulty for young people with ADHD (Barkley, 1998). Some of the young people in this study described how relationships

with their parents could be difficult as a result of their excitability and hyperactive behaviour. At the same time they also described their immense need to spend time with their parents; to experience intimacy and closeness with their parents; to be listened to and heard, understood and approved.

The importance of parents for children and adolescents has been widely researched and discussed in Iceland in recent years. Several Icelandic studies have demonstrated that if parents spend time with their adolescent children, it has a positive effect on the adolescents' lives in many ways, such as reducing the risk of substance abuse. Adolescents are also more likely to feel happier at school if they have a close nurturing relationship with their parents (Kristjánsson et al., 2006; Kristjánsson et al., 2005), as well as being at lower risk of experiencing various psychological and sociological problems (Thorlindsson and Vilhjalmsdóttir, 1991; Sigfusdóttir et al., 2004). Nevertheless, the young people in this study explained that it is not always easy to have a child with ADHD and that some parents find it terribly difficult and 'just can't cope with it'. Research in Iceland and elsewhere has shown that raising a child with ADHD can place enormous strain on the family (Sæmundsdóttir, 2003; Barkley, 1998), and parents of children with ADHD often experience considerable stress in their parenting roles and worry about their children (Sæmundsdóttir, 2003; Anastopoulos et al., 1992; Bull and Whelan, 2006). In addition, some parents suffer from depression, anxiety and marital difficulties (Lahey et al., 1988). Parenting styles are also known to affect young people's self-esteem and well-being (Aðalbjarnardóttir and Garðarsdóttir, 2004a; Aðalbjarnardóttir and Garðarsdóttir, 2004b). Research has shown that parents of children with ADHD have negative self-esteem as parents (Sæmundsdóttir, 2003) and often become overly directive and negative in their parenting style (Cunningham and Barkley, 1979). Is it possible that the enormous strain that many families of young people

with ADHD experience in their everyday lives affects some parents' ability to form the close, intimate relationships their children so badly need?

#### **6.4. The need for emotional support**

The young people reported their need for support. Their sources of emotional support were parents, friends, peers and pets, brothers and sisters. Relationships with friends were obviously of great importance for all the adolescents and were proportionally most discussed in the dialogues. The young people explained how friends offer them emotional support at difficult times and help them in many ways, for example by backing them up if they get into trouble or are feeling bad. In her study of 74 teenagers with diabetes, La Greca (1992) found that although family members were mentioned more often as source of support and helped more than friends, e.g. with medical tasks, friends were particularly important for providing emotional support and companionship. In Lightfoot et al.'s (1999) study, close friends at school were found to help the ill and disabled children in many ways, e.g. by helping them to deal with curiosity, by explaining their condition for those who asked questions, and by 'sticking up' for the young person if they were being bullied.

In the present study many of the young people described experiencing difficulties in their relationships with friends and some of them expressed the feeling of not being 'meant to have any friends' as all relationships with friends went wrong and the friends would suddenly stop being friends. The young people described their sense of being different and alone, and how they feared rejection by their peers and so did not dare to talk to them. In a study by Hoza et al. (2005), over half of children with ADHD were found to be rejected by peers, compared to 15% of children generally (Hoza et al., 2005). Furthermore, difficulties in relationships with friends were also found in Lightfoot et al.'s (1999) research on ill and



disabled young people, including being ignored by peers and being the focus of curiosity. Research also shows that peer rejections are associated with behaviours such as verbal and physical aggression, disruptive attempts to enter new groups and negative classroom behaviour like being quick-tempered, violating the rules and arguing (Guevremont and Dumas, 1994). Several youngsters in the study described their own behaviour in some of these terms. However, in my findings the young people explain how vital it is to have self-knowledge as it can help them to discover ways of handling themselves better. If they know they are aggressive or have destructive tendencies they can try to stop themselves and find ways of not taking out their aggression on other people.

Some of the young people mentioned that they had been bullied for years by their schoolmates. Lightfoot et al. (1999) found that over a third of the children in their study had been bullied and most of the bullying took the form of verbal abuse, being laughed at and name-calling. Nordhagen et al. (2005) found in a cross-sectional comparative study where parents answered questionnaires that children with chronic health conditions, especially those with psychiatric/nervous problems and hyperactivity, were at a heightened risk of becoming the victims of bullying.

From the young people's accounts it is clear that knowledge rather than prejudice in their environment, i.e. on the part of friends and adults, can help. If people know about their ADHD they can inform them if their behaviour is irritating and help them to relax. Moreover, knowledge enables friends to understand their behaviour and personality better. However, some of the young people pointed out the necessity of choosing only a few, trusted friends to tell, so that knowledge of their ADHD would not be used for bullying or teasing. In Lightfoot et al.'s (1999) research the young people's views differed as to whether peers should know about their illness or disability. As in the present study, one reason for

wanting peers to know was that it would make them more understanding. On the other hand, the reason for not wanting peers to know, according to Lightfoot et al. (1999), was that some pupils were keen to maintain their privacy.

In the present study the young people reported how they experienced the importance of pets in their lives. Rose had suffered many bad experiences in her life and stated that her life had been 'like a hell' at times. She explained the importance of her cat in her life and how he was the only living creature she could trust and tell everything, and how he understood and comforted her when she was feeling bad. McNicholas and Collis (2001) showed in their research that children select animals as significant relationships, regarding their pets as their special friends and companions. They found pets to be potential sources of comfort when a child is ill or scared, as well as being a playmate to share a special secret with (McNicholas and Collis, 2001). Moreover, pets have a positive influence on children's self-esteem (Van Houtte and Jarvis, 1995; McNicholas and Collis, 2001).

From the young people's accounts it was evident that the support of elder brothers and sisters was important. The siblings of the young people in the present study were young adults in their twenties and most of them lived by themselves. The relationships were close and the elder brothers and sisters helped the young people by encouraging them when something had gone wrong or they were feeling bad. I did not find any research that supported the findings from this perspective, that is, from the perspective of young people with ADHD. On the other hand Kendall's (1999) qualitative study with siblings living in a family with an ADHD child found many negative and few positive consequences for the siblings. The negative effects were the use of aggression and violence from children with ADHD toward their siblings and the feelings of anger, guilt and resentment frequently

experienced by the siblings; the positive effects were the positive aspects of caregiving, in that they experienced that they had a ‘special’ role in their ADHD sibling’s life.

## **6.5. The need for caring teachers**

Caring in education has been proposed as the primary aim of every educational institution (Noddings, 1984), with caring relations as a basis for pedagogical activity (Noddings, 2005). Yet the findings of this study show that many young people with ADHD experience school as the most difficult area of their lives, as a result of their educational and emotional problems and difficult relationships with schoolmates and school staff. Other studies have produced similar findings (Barkley, 1998). These difficult school experiences can be so painful that on some days the young people in my study did not even manage to attend school. From the young people’s perspective, the importance of their relationship with their teachers is obvious, as is their need to feel cared for by their teachers. In the findings the young people describe how ‘kind’ and ‘understanding’ teachers listened to them and calmed them down so that their irritation ‘just went away’. In Lightfoot et al.’s (1999) research understanding teachers were also found to be of great importance. Understanding teachers were described as being aware of the pupils’ health condition, understanding its impact on their school life, and offering appropriate support based on this understanding (Lightfoot et al., 1999). Lightfoot et al. (1999) also found that the young people had developed special emotionally supportive relationships with individual teachers, where some teachers took an active role in supporting and encouraging them at school. In the present study one of the youngsters had this kind of relationship with his art teacher who encouraged him and praised his work when he was experiencing difficult relationships with some of the other teachers. This supportive relationship had an immensely positive significance for my young person and made him feel better about himself. Noddings (1984) proposes that the caring teacher

should listen to the student and connect with him/her in dialogue, learning about his/her needs, interests and talents, helping the student to bring interests and topics together in ways that have meaning for him or her. In the present study the young people explained how possessing self-knowledge and the ability to know their own strengths and build on them was important and helpful. When they were doing something they knew they could do well, it made them feel good about themselves and they experienced happiness. This is supported by a case study by Schirduan and Case (2004) who found that if young people with ADHD were provided with a curriculum that catered to their strengths, the students expressed a higher level of competence and self-assuredness than has been found among students with ADHD in more traditional curricular settings.

In Halldorsdottir's (1990) phenomenological research with nursing students, she found that students' responses to a professional, caring teacher-student relationship were: a sense of acceptance and self-worth; personal and professional growth and motivation; appreciation and role-modelling, and long-term gratitude and respect. In the construction phase of the present study I also found this sense of acceptance and self-worth in the young people who had experienced caring teacher-student relationships, together with gratitude and respect for the teachers.

In the present study one of the youngsters explained how her teachers almost bullied her and her friend (who also had ADHD); they were always telling them off and did neither listen to them nor know about their needs. This relationship with the teachers made her and her friend feel so 'incredibly' bad that they could not attend school for a week. This sense of being victimized, suffering and feeling that the teacher was against them was also found in Halldorsdottir's (1990) study, as a result of uncaring teachers' relations with their students. Halldorsdottir (1990) found in addition that uncaring teachers show a lack of professional

competence and concern as well as a desire for control and power. Further, they exhibit destructive behaviour characterized, for example, by showing the student contempt and complete disrespect, or totally ignoring him/her as a person with devastating results.

## **6.6. The need for a caring school nurse**

The goal of nursing and health care is to increase people's health and well-being (Halldorsdottir, 1996). The present study reveals the young people's vulnerability; their self-esteem is vulnerable and some of them have experienced bullying, prejudice, loneliness and hopelessness in life. As shown in the findings, the hopelessness of young people with ADHD can be both psychologically and physically life threatening. This was described to me by one of the youngsters who began to have suicidal thoughts when she was nine years old.

For the two young people who experienced the most problems at school with bullying and other difficulties, the school nurse was the only person they could talk to about their difficulties. However, other youngsters did not mention the school nurse as a potential source of support. In an Icelandic study, Sæmundsdóttir (2003) asked parents of children with ADHD which staff members at school had offered the most support and understanding. Almost half the parents answered that the teachers were most supportive and understanding and only 15% mentioned the school nurse. However, these results from parents do not necessarily reflect children's experiences of support and understanding.

In Lightfoot et al.'s (1999) research on ill or disabled school children, the young people did not regard the school health service as a potential source of support for several reasons.

They perceived school nurses as being responsible for the general health checks given to all

pupils and not as someone to talk to about worries related to their illnesses. Also, the school nurses were rarely available at times when the pupils wanted to speak to them. In addition, some children who had consulted their school doctor or nurse commented that they were surprised to discover that these professionals had very little knowledge about their individual case or treatment. Therefore, they decided not to approach these professionals in the future. Support from school health staff has not yet been explored in Iceland from the perspective of children and adolescents with ADHD. Nevertheless, from my own experience of working as a school nurse in Iceland I believe all of these comments by children from the UK are relevant also for Iceland. In my opinion there is scope for school nurses to play a larger role in helping these pupils and providing more services for them and their families within the school. In Icelandic research on the service needs of pupils with special health-care needs, where educational professionals, health-care professionals and parents were consulted, it was found that a multidisciplinary approach was needed to improve the service offered to the children (Iceland, Primary Health Care of the Capital Area, 2005). In addition, the human resources serving the children in schools, e.g. school nurses, need to be supported and strengthened by, for example, giving them the opportunity to increase their knowledge and to consult specialists when necessary.

## **6.7. Limitations and strengths of the study**

From the beginning, the focus of the study was very broad and in the dialogues I approached the adolescents with wide-open questions. However, I soon acknowledged that this broad focus was not suitable for all the young people as they were differently verbally developed and a few of the dialogues with the younger adolescents were very short. At some point in the first weeks when I was taking the interviews, I recognized this as a limitation of the study. I was afraid that I would not get enough material and that I would not be able to

construct any deep meaning from the young people's experiences. However, during the analysis phase when I was constructing the themes I found that these short dialogues strengthened the findings in the longer dialogues with the more verbal adolescents and that the younger adolescents were to some extent experiencing 'here and now' something the older adolescents were explaining in more depth and reflecting on in their dialogues. However, to give the youngest and less verbal young people an opportunity to express themselves better, it might have helped to use some means of non-verbal communication such as drawings, as Lightfoot et al. (1999) explain. They used 'map' drawings among other interview techniques to enable the young people to express themselves non-verbally.

A further limitation was the difficulty I experienced in acquiring ten participants for the sample. Perhaps I would have been more successful if I had accessed them through the school system, through the teachers for instance (see Lightfoot et al., 1999, who used this method of access in their studies).

One of the strengths of the study was the heterogeneity of the sample. The young people exhibited a range of different ADHD core symptoms and comorbidities, which affected their lives in a variety of ways; some of the young people had primarily positive experiences while others had negative ones. Their social circumstances were also very different; their family-type varied greatly and they came from all over the country (see Table 4.1). I believe that a further strength of the study was the incredible degree of trust that many of the young people showed me, which enabled them to describe many of their concerns in considerable depth.

## 6.8. Summary

In this chapter the findings of the study were discussed and related to the relevant literature. Research into the needs of young people with ADHD could not be found in the literature, although some of their support needs were found to be similar to those of young people with illnesses or chronic disabilities. This and other studies show that it can be difficult to be a young person with ADHD, not least in elementary school. The problems that young people with ADHD experience at school have a huge impact on their lives, often in the most detrimental sense, resulting in negative self-perception and unhappiness. However, the young people also exhibit many great strengths, interests and talents, and it is extremely important for their health and well-being that they should build on these in order to experience positive feelings and a strong self-image. Furthermore, as the young people themselves explained, they can be supported effectively by parents, peers and pets, as well as by elder brothers and sisters, and caring teachers and school nurses. It is our moral duty to care for children with ADHD in our society in order to ensure that they achieve the best possible development. The human resources of creativeness and energy found in people with ADHD are something we cannot afford not to take advantage of in our constantly evolving society. Yet for this to happen, we need to ‘look through their eyes’, listen to them and hear them, and fulfil their overriding need: *the need to be accepted as they are*.

The next chapter gives recommendations for practice and further research based on the findings of this study.



## **7. Conclusion**

In chapter six I discussed the findings of the study in which the research question was: ‘What is the lived experience of ADHD from the perspective of adolescents with emphasis on their self-reported needs?’ The data arising from this research on the perspective of adolescents with ADHD gave rise to many ideas for better practice in order to increase the well-being of the young people. The findings also provided many ideas for further research that I feel is necessary to enhance knowledge of the issues of young people with ADHD. In this last chapter I will make recommendations for professional practice and further research.

### **7.1. Recommendation for practice**

- ❖ More education about ADHD is necessary for school nurses, teachers and other school staff.
- ❖ More information about ADHD is needed in society, via the media, leaflets and other means, to increase knowledge and reduce prejudice. School nurses are in an excellent position to inform the school community, e.g. teachers, students and parents.
- ❖ School nurses need to develop a close supportive relationship with the individual young person with ADHD and his/her family.
- ❖ School nurses need to work actively with others in the school community to fulfil the needs of the individual young person and his/her family.
- ❖ Parents, peers and pets, elder brothers and sisters need to be acknowledged as important sources of support for children with ADHD.

## **7.2. Recommendation for further research**

- ❖ Qualitative studies on support in schools for children and adolescents with ADHD, from the perspective of the young people themselves. These could provide better understanding of the subject and could prove valuable in developing the health-care service in schools.
- ❖ Qualitative and quantitative studies of the influence of peers on young people with ADHD as well as the quality of their friendships, from the perspective of the young people themselves.
- ❖ Qualitative and quantitative studies of the influence of pets on young people with ADHD from the perspective of the young people themselves.
- ❖ Qualitative and quantitative studies of the influence of elder brothers and sisters on young people with ADHD.
- ❖ Qualitative and quantitative studies of the depth and dimensions of relationships of young people with ADHD with their parents, which could provide the understanding needed by health-care professionals and others to support the families.
- ❖ Studies on the self-perception of young people with ADHD in Iceland.
- ❖ Studies on bullying among young people with ADHD in Iceland.
- ❖ Qualitative and quantitative studies on hope in young people with ADHD.
- ❖ Qualitative and quantitative studies
- ❖ Qualitative and quantitative studies identifying the role of the school nurse in schools e.g. exploring the role of school nurse in meeting the special needs of pupils with ADHD.
- ❖ Qualitative studies exploring the ‘interface’ between nursing and the health-related work of teachers and other staff in schools.

## **Appendices**

### **Appendix I**

Information about the study to the president of ADHD Association – English version/ Icelandic version

### **Appendix II**

A letter from the National Bioethics Committee

### **Appendix III**

A framework for interviews – English version/ Icelandic version

### **Appendix IV**

A letter to the National Bioethics Committee –  
English version/ Icelandic version

### **Appendix V**

Approval from the Bioethics Committee

### **Appendix VI**

Advertisement about the study to the co-researcher –  
English version/ Icelandic version

### **Appendix VII**

Information about the study to the co-researchers –  
English version/Icelandic version

### **Appendix VIII**

Notification to the Data Protection Authority –  
English version/ Icelandic version

### **Appendix IX**

Informed consent form – English version/ Icelandic version

### **Appendix X**

Declaration from the English translator

## **Appendix I**

**Information about the study to the president of ADHD Association – English  
version/Icelandic version**

Hafnarfjörður, 22 September 2006

Dear

I the undersigned, Áslaug Birna Ólafsdóttir, am a healthcare nurse, and also studying for my MSc at the Royal College of Nursing, Manchester, by distance studies through the University of Akureyri.

I worked for many years as a school nurse, and became very interested in the subject of children with ADHD. I became aware of great ignorance about how they felt and their situation, and prejudice against them and their families.

I am now approaching the completion of my MSc studies, and I am working on my 30-credit MSc dissertation, on children and adolescents living with ADHD. My supervisor is Professor Sigríður Halldórsdóttir of the University of Akureyri. The study is a qualitative, phenomenological study carried out through dialogues. The objective is to open a window into the lives of children and adolescents with ADHD, to enhance understanding of their circumstances and how they feel, and to reduce prejudices against them and their families.

The sample comprises 12-14 Icelandic children and adolescents aged 11 to 16 years. The study is performed according to the guidelines of the "Vancouver School"; it is carried out in such a way that I meet each child/adolescent once or twice for a dialogue of about 60 minutes, during which they describe to me what it is like to live with a mental disorder such as ADHD, what is most helpful to them, and what is most difficult. The dialogues are then analysed and interpreted in accord with the guidelines of the Vancouver School.

The study has been approved by the Bioethics Committee, and has been allocated a grant from the B Section of the Icelandic Nurses' Association Research and Science Fund.

Sincerely

Áslaug Birna Ólafsdóttir  
Miðvangur 109  
220 Hafnarfjörður  
Tel: 555 0537 and 690 4733

Hafnarfjörður 22.september 2006

Sæ

Ég undirrituð, Áslaug Birna Ólafsdóttir, er heilsugæsluhjúkrunarfræðingur í meistaranámi við Royal Collage of Nursing, Manchester, fjarnám við Háskólann á Akureyri.

Ég vann í mörg ár sem skólahjúkrunarfræðingur og fékk þá mikinn áhuga á málefnum barna með ADHD. Varð ég vör við mikla vanþekkingu á þeirra líðan og aðstæðum sem og fordómum í þeirra garð og fjölskyldna þeirra.

Það líður að lokum í mínu meistaranámi og ég er nú að gera mína 30 eininga meistaranámsókn um börn og unglunga með ADHD. Leiðbeinandi minn er Sigríður Halldórsdóttir prófessor við Háskólann á Akureyri. Rannsóknin er eigindleg, fyrirbærafræðileg samræðuranámsókn með það að markmiði að opna glugga inn í líf barna og unglunga með ADHD, auka skilninga á þeirra aðstæðum og líðan og minnka fordóma gagnvart þeim og fjölskyldum þeirra.

Úrtakið er u.þ.b. 12-14 íslensk börn og unglingar á aldrinum 11-16 ára. Rannsóknin er unnin samkvæmt leiðbeiningum "Vancouver skólans" og fer þannig fram að ég hitti börnin/unglingana 1-2 sinnum og á u.þ.b. 60 mín samræður við þau þar sem þau lýsa fyrir mér hvernig það er að lifa með geðröskun eins og ADHD og hvað það er sem hjálpar þeim mest og hvað það er sem er erfiðast. Viðtölin eru síðan greind og túlkuð eftir leiðbeiningum Vancouver skólans.

Rannsóknin hefur fengið leyfi frá Vísindasiðanefnd, einnig hefur hún hlotið styrk ú B-hluta Vísindasjóðs Félags íslenskra hjúkrunarfræðinga.

Besta kveðja

Áslaug Birna Ólafsdóttir  
Miðvangi 109  
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S: 555 0537 og 690 4733

## **Appendix II**

### **A letter from the National Bioethics Committee**



**VÍSINDASÍÐANEFND**  
**National Bioethics Committee**

Vegmúli 3, 108 Reykjavík,

Tel: 551 7100, Fax: 551 1444

e-mail: visindasidanefnd@vsn.stjr.is

Háskólinn á Akureyri, Heilbrigðisdeild  
Sigríður Halldórsdóttir, prófessor  
Háskólinn á Akureyri  
Pósthólf 224  
602 Akureyri

Reykjavík, January 12, 2006

Ref: VSNb2005120015/03-7 Námsverkefni - nemarannsóknir almennar/BH/—

**Regarding: 05-159-afg Upplifun barna og unglunga af þeirri reynslu að lifa með ADHD:  
Fyrirbærafræðileg rannsókn.**

At its meeting of January 10<sup>th</sup> 2006, the National Bioethics Committee (NBC) discussed your application, dated December 19<sup>th</sup> 2005, concerning the research project "Upplifun barna og unglunga af þeirri reynslu að lifa með ADHD: Fyrirbærafræðileg rannsókn". The project constitutes the work of Áslaug Birna Ólafsdóttir towards a Masters degree in Nursing at the Royal College of nursing in London/Manchester. Enclosed with your application were copies of the research protocol, the information sheets and consent form for participants.

Participants will be approx. 10 Icelandic children and teenagers, age 11-16 years old diagnosed with ADHD (Attention Deficit /Hyperactivity Disorder). Parents of the participants will be asked to sign a consent form for the participants. The project is of a qualitative nature, in accordance with the Vancouver school methodology. Participants will participate in interviews, where they will discuss their experience of living with ADHD.

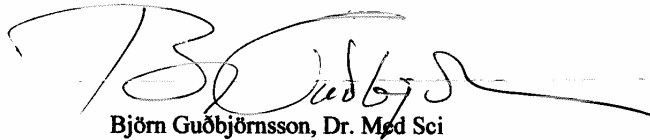
The National Bioethics Committee would like to make the following comments and requests:

1. The NBC requests that a specific information sheet be designed for the participants, taking into account their cognitive development and special needs.
2. It is also requested, if the intention is to make use of the researcher's personal network to acquire participants, that such utilisation be limited to a professional network, rather than going through family or friends.
3. The Committee requests that it be sent a framework for the interviews.
4. The informational material should state that declining participation at any stage of the project will have no effect on any service offered to the participants.



Your research proposal will be taken into final consideration by the NBC upon receipt of your response to the above-mentioned comments and requests. Please note that commencement of the research project is not permitted until final approval from the National Bioethics Committee has been obtained.

Respectfully Yours,  
on behalf of the National Bioethics Committee,

A handwritten signature in black ink, appearing to read 'Björn Guðbjörnsson', with a long horizontal flourish extending to the right.

Björn Guðbjörnsson, Dr. Med Sci

## **Appendix III**

### **A framework for interviews – English version/Icelandic version**

## **The lived experience of children and adolescents living with ADHD: A phenomenological study**

### **Interview framework**

#### **Time and place:**

The children/adolescents and their parents jointly decide where the dialogues are to take place, e.g. in the home, or somewhere else where the child/adolescent feels secure and relaxed. It is necessary that the setting should be private, without outside stimuli or disturbances.

#### **Who will be present at the dialogue?**

It is important that the child/adolescent and the researcher (Áslaug Birna Ólafsdóttir) converse together in privacy, without the parents' presence, in order that the young people be able to express themselves freely, which might not be the case in the parents' presence.<sup>3 4 5</sup>

This is, of course, contingent upon the consent of the parents and the child/adolescent.

Parents want to safeguard their children. Some might perceive this as a threat to the child, and feel unable to consent to the child's participation in the study. It is also possible that some children/adolescents would be unwilling to participate in a dialogue without their parents.

#### **Duration of dialogue:**

Approximately 60 minutes, but duration will vary according to how long the child/adolescent can maintain concentration, and how soon he/she becomes tired, which is very variable in children of this age (11-16 years). Hyperactivity and attention deficit may also vary between individuals. It is important to observe the children/adolescents carefully, so that they can take breaks as needed, or terminate the dialogue.

#### **Recording of dialogues:**

---

<sup>3</sup> Coyne, I.T. (1998) Researching children: some methodological and ethical considerations, *Journal of Clinical Nursing*, 7 (5), pp.409-416.

<sup>4</sup> Allmark, P. (2002) The ethics of research with children, *Nurse Researcher*, 10 (2), pp.7-19.

<sup>5</sup> Miller, S. (2000) Researching children: issues arising from a phenomenological study with children who have diabetes mellitus, *Journal of Advanced Nursing*, 31(5), pp.1228-1234.

The dialogues will be audiotaped. They will then be transcribed and analysed. This is explained to the children/adolescents at the start of the dialogue.

**Dialogue technique:**

In my work as a school nurse I have gained extensive experience of talking to children and adolescents under various circumstances. In my view it is most important to show them respect and warmth, smile at them, allow them to feel that they and their opinions are important, and never to patronise them. They will then relax, and are able to trust the adult. In order to reduce the “adult status” of the researcher, one can for instance wear informal clothes, sit at the same level as the children, e.g. on the floor or on a sofa, and use simple, clear language in the dialogue.

**What will be discussed?**

Examples of questions:

Tell me about an ordinary day in your life.

What is it like to be a girl/boy with ADHD?

How do you feel at school? At home? With your friends?

How do you feel you get on with e.g. other kids, your siblings, your parents, your teacher?

How do people behave towards you: other kids, adults, e.g. at school?

What do you feel is helpful to you, and makes you stronger, e.g. at school, at home, with your friends?

What do you feel isn't helpful, or even has a bad effect on you, e.g. at school, at home, with your friends?

**At the beginning of the dialogue it will be clarified that the child/adolescent:**

Can withdraw from participation at any time he/she wishes, without giving any explanation, and that it will not have any effect upon the service he/she receives.

Need not answer any question unless he/she want to, without giving any explanation.

Should say 'pass' if he/she does not wish to answer a question.

Should tell me if he/she is tired and wants a break, or wants to terminate the dialogue, in which case we will take a break or stop the dialogue.

**Will any payment be made for the dialogue?**

No, but they will receive sincere thanks, and be given a small gift as a memento.

They will also be sent a copy of the dissertation when it is finished, if they wish.

## Upplifun barna og unglunga af þeirri reynslu að lifa með ADHD: Fyrirbærafræðileg rannsókn.

### Viðtalsrammi.

Staður og stund:

Börnin/unglingarnir og foreldrar þeirra ákveða í sameiningu hvar og hvenær samtölin fara fram, t.d. á heimili barnsins eða einhversstaðar annars staðar þar sem barnið/unglingurinn finnur fyrir öryggi og líður vel. Nauðsynlegt er að það sé næði, ekki utanaðkomandi áreiti eða truflanir.

### Hverjir verða viðstaddir í viðtalinu?

Það er mikilvægt að barnið/unglingurinn og rannsakandinn (Áslaug Birna Ólafsdóttir) ræði saman í næði og án þess að foreldarnir séu viðstaddir til þess að gera þeim kleift að tjá sig um allt sem þau vilja og sem þau myndu e.t.v. ekki gera í návist foreldra sinna<sup>678</sup>.

Þetta er þó að sjálfsögðu háð samþykki bæði foreldranna og barnanna/unglinganna.

Foreldrar vilja tryggja öryggi barna sinna og sumir foreldrar gætu upplifað þetta sem ógn við öryggi barnanna og myndu því ekki geta samþykkt þátttöku barnsins í rannsókninni. Eins er möguleiki að einhver börn/unglingar geti ekki hugsað sér að taka þátt í viðtali án foreldra sinna.

### Lengd viðtalsins:

U.þ.b.60 mínútur. Fer þó eftir því hvað barnið/unglingurinn hefur lengi einbeitingu og hvað hann/hún þreytist fljótt sem getur verið mjög mismunandi fyrir börn á þessum aldri (11-16 ára) og eins getur ofvirknin og einbeitingarskorturinn verið mismikill eftir einstaklingum. Nauðsynlegt er að fylgjast vel með börnunum/unglingunum og hvíla eftir þörfum eða stoppa viðtalið.

### Upptaka viðtalsins:

Viðtölin verða tekin upp á segulbandstæki. Síðan verða viðtölin vélrituð og greind. Þetta er útskýrt fyrir börnunum/unglingunum í upphafi viðtalsins.

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<sup>6</sup> Coyne, I.T. (1998) Researching children: some methodological and ethical considerations, *Journal of Clinical Nursing*, 7 (5), pp.409-416.

<sup>7</sup> Allmark, P. (2002) The ethics of research with children, *Nurse Researcher*, 10 (2), pp.7-19.

<sup>8</sup> Miller, S. (2000) Researching children: issues arising from a phenomenological study with children who have diabetes mellitus, *Journal of Advanced Nursing*, 31(5), pp.1228-1234.

**Viðtalstækni:**

Í starfi mínu sem skólahjúkrunarfræðingur hef ég öðlast mikla reynslu í að tala við börn og unglinga í ýmsum aðstæðum. Að mínu áliti er mikilvægast að sýna þeim virðingu, hlýju, brosa til þeirra og láta þau finna að þau er mikilvæg og þeirra skoðanir, aldrei að tala niður til þeirra. Þá slaka þau á og hafa möguleika á að treysta hinum fullorðna. Til að minnka fullorðinsstatus rannsakandans er t.d. hægt að vera í látlausum fatnaði, sitja í sömu hæð og börnin t.d. á gólfinu eða í sóffa og nota einfalt og skýrt tungumál í viðtölunum.

**Um hvað verður rætt?**

Dæmi um spurningar:

Lýstu fyrir mér venjulegum degi í lífi þínu.

Hvernig er að vera strákur/stelpa með ADHD?

Hvernig líður þér í skólanum, heima, með vinum?

Hvernig finnst þér samskipti þín vera t.d. við aðra krakka, systkini þín, foreldra þína og kennarann þinn?

Hvernig kemur fólk fram við þig: aðrir krakkar, fullorðnir, t.d. í skólanum?

Hvað finnst þér hjálpa þér og styrkja þig og efla þig t.d. í skólanum, heima, með vinum?

Hvað finnst þér ekki hjálpa þér, jafnvel virka illa á þig t.d. í skólanum, heima, með vinum?

**Það verður ítrekað í upphafi samtalsins að barnið/unglingurinn:**

Megi hætta við þátttöku í rannsókninni hvenær sem hann/hún vilji án þess að útskýra það nokkuð og það hafi ekki nein áhrif á þjónustu sem hann/hún fær.

Þurfi ekki að svara neinum spurningum nema hann/hún vilji án þess að útskýra það nokkuð.

Skuli segja ‘pass’ ef hann/hún vilji ekki svara spurningu.

Skuli segja mér ef hann/hún er þreyttur og vill hvíla sig eða hætta samtalinu og þá stoppum við og hvílum eða hættum.

**Verður borgað fyrir viðtalið?**

Nei, en þeim verður mjög vel þakkað og gefin lítil gjöf til minningar og fá senda rannsóknina þegar hún er tilbúin ef þau óska eftir því.

## **Appendix IV**

**A letter to the National Bioethics Committee – English version/Icelandic version**

Hafnarfjörður, 1 February 2006

**Re: 05-159-afg The lived experience of children and adolescents living with ADHD:  
A phenomenological study**

Dear Bioethics Committee

In your letter dated 12 January 2006 the following questions were asked and points raised:

1. that a special information sheet for participants should be prepared, taking account of the children's stage of development and their special needs.
2. that if participants were to be found through a personal network, this should be confined to the professional network, and not friends and relatives.
3. that a special interview framework be prepared.
4. that the information sheet should specify that participants can withdraw from participation at any point in the study, and that this will have no effect on the service they receive.

**Answers to points raised and questions:**

1. See appended information sheets, advertisement and informed consent form, which have been designed with the stage of development of the children and their needs in mind. Efforts were made to provide information in simple, clear form, and to answer questions to which the children need to have answers.
2. If sufficient participation cannot be achieved through the ADHD Association, the intention is to contact school nurses in the capital area and in the regions, and to ask them to pass on the advertisement/information sheet to parents with whom they are in contact. Participants will not be found via friends or relatives.
3. See appended interview framework.
4. See appended information sheet, which states that participants can withdraw from participation at any point in the study, and that this will have no effect on the service they receive.

In hope that my application will be considered by the Bioethics Committee as soon as possible.

Sincerely

---

Áslaug Birna Ólafsdóttir,  
Miðvangur 109,  
220 Hafnarfjörður  
Tel: 555 0537 and 690 4733



Hafnarfjörður 1.febrúar 2006

**Varðandi: 05-159-afg Upplifun barna og unglinga af þeirri reynslu að lifa með ADHD: Fyrirbærafræðileg rannsókn.**

Kæra Vísindasiðanefnd.

Samkvæmd bréfi ykkar dagsett 12.janúar 2006 voru eftirfarandi spurningar og athugasemdir settar fram:

að sérstakt upplýsingablað til þátttakenda yrði búið til þar sem tekið er mið af þroska barnanna og sérstökum þörfum þeirra.

að ef þátttakendur yrðu fundnir í gegnum persónulegt tengslanet að það yrði takmarkað við faglegt tengslanet en ekki farið til vana og ættingja.

að búinn yrði til sérstakur viðtalsrammi fyrir viðtölin.

að tekið sé fram á upplýsingablaðinu að þátttakendur geti hætt við þátttöku á öllum stigum rannsóknarinnar án þess það hafi nokkur áhrif á þjónustu sem þeim er veitt.

**Svör við athugasemdum og spurningum:**

Sjá meðfylgjandi upplýsingablöð, auglýsingu og upplýst samþykki sem hafa verið hönnuð með þroska barnanna og þeirra þarfir í huga. Leitast var við að hafa upplýsingarnar einfaldar og skýrar og að svara þeim spurningum sem nauðsynlegt er að börnin hafi svör við.

Ef nægjanleg þátttaka fæst ekki í gegnum ADHD félagið er áætlað að leita til skólahjúkrunarfræðinga á höfuðborgarsvæðinu og út á landi og biðja þá að afhenda auglýsinguna/upplýsingabréfið til foreldra sem þær eru í tengslum við. Þátttakendur verða ekki fundnir í gengum vini eða ættingja.

Sjá meðfylgjandi viðtalsramma.

Sjá meðfylgjandi upplýsingablað þar sem tekið er fram að þátttakendur geti hætt við þátttöku hvenær sem er án þess að það hafi nokkur áhrif á þjónustu sem þeim er veitt.

Með von um að erindi mitt verði sem fyrst tekið fyrir á fundi Vísindasiðanefndar.

Virðingarfyllst,

---

Áslaug Birna Ólafsdóttir,  
Miðvangi 109,  
220 Hafnarfjörður  
S: 555 0537 og 690 4733

## **Appendix V**

### **Approval from the Bioethics Committee**

# AFRIT

Háskólinn á Akureyri, Heilbrigðisdeild  
Sigríður Halldórsdóttir, prófessor  
Sólborg v/Norðurslóð  
601 Akureyri



VÍSINDASIÐANEFND  
National Bioethics Committee

Vegmúli 3, 108 Reykjavík,

Tel: 551 7100, Fax: 551 1444

e-mail: visindasidanefnd@vsn.stjr.is

Reykjavík, February 7, 2006

Ref: VSNb2005120015/03-7 Námsverkefni - nemarannsóknir almennar/BH/-

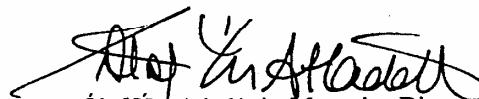
**Regarding. 05-159-S1 Upplifun barna og unglunga af þeirri reynslu að lifa með ADHD:  
Fyrirbærafræðileg rannsókn.**

The National Bioethics Committee has received your response, dated February 1st 2006, to the committee's requests and comments stated in a letter dated January 12th 2006, concerning the above-mentioned research project.

The National Bioethics Committee hereby grants your research proposal it's full approval.

The National Bioethics Committee kindly requests that researchers include the given referral no. given to their project by the committee in published research papers. The National Bioethics Committee would also like to receive copies of research papers portraying research approved by the committee.

Respectfully yours,  
on behalf of the National Bioethics Committee,

  
Ólöf Ýr Atladóttir, Managing Director

Copy to Áslaugu Birnu Ólafsdóttur, Miðvangi 109 220 Hafnarfirði.

## **Appendix VI**

**Advertisement about the study to the prospective co-researcher – English  
version/Icelandic version**



Being a child with attention deficit and hyperactivity  
Research  
January 2006-January 2007

This advertisement is for boys and girls with ADHD aged 11 to 16, and their parents

I worked for many years as a school nurse, and met girls and boys with ADHD. I feel that people often know little about ADHD, and that they don't understand how boys and girls with ADHD feel. In this research I am going to listen to boys and girls talk about their experience of having ADHD.

The objective of the research is to help families, friends and people who work with children and teenagers to know more about ADHD and understand better what it is like to have ADHD. The objective is also for people to find out what is most helpful for you.

This study is my final project in my MSc studies in nursing at the Royal College of Nursing in London/Manchester University, which is in collaboration with the University of Akureyri.

Icelandic girls and boys with ADHD aged 11 to 16 are invited to take part in the research. If a large number of people contact me, I will choose who to include in the study. For instance, I also have to include youngsters in the study from outside the capital area.

**Research supervisor:**

Sigríður Halldórsdóttir, Professor of Nursing,  
University of Akureyri, PO Box 224, 602 Akureyri  
Work phone: 460 8000. E-mail: [sigridur@unak.is](mailto:sigridur@unak.is)

If you would like more information, or if you are interested in taking part, phone NN on tel. xxx An information sheet can also be mailed.  
If you get in touch, you are not committed to taking part, but only expressing an interest in more information.

With kind regards, and in hopes of a good response,

---

NN, nurse  
Tel: xxxxxxx  
Adress: xxx

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Prof. Sigríður Halldórsdóttir,  
e-mail: sigridur@unak.is  
University of Akureyri



Að vera barn með ofvirkni og athyglisbrest  
Rannsókn  
Janúar 2006-Janúar 2007

Þessi auglýsing er fyrir stráka og stelpur með ADHD 11-16 ára og foreldra þeirra

Ég heiti Áslaug Birna og ég vann í mörg ár sem skólahjúkrunarfræðingur og hitti stelpur og stráka með ADHD. Mér finnst fólk oft ekki vita mikið um ADHD og ekki skilja hvernig stelpum og strákum með ADHD líður. Í þessari rannsókn ætla ég að hlusta á stráka og stelpur með ADHD og skrifa um þeirra reynslu.

Rannsóknin er gerð til að fjölskyldur, vinir og þeir sem vinna með börnum og unglingum viti meira og skilji betur hvernig það er að vera með ADHD. T.d. er mikilvægt að fólk fái að vita hvað það er sem hjálpar ykkur best.

Rannsóknin er lokaverkefni mitt í meistaranámi í hjúkrunarfræði við Royal College of Nursing í London/Manchester háskóla sem er í samstarfi við Háskólann á Akureyri.

Íslenskum stelpum og strákum með ADHD 11-16 ára, er boðið að vera með í rannsókninni. Ef margir hafa samband við mig þá vel ég hverjir verða með í rannsókninni. T.d. er mikilvægt að líka þeir sem búa utan höfuðborgarsvæðisins fái að segja frá sinni reynslu.

Ábyrgðarmaður rannsóknarinnar:  
Sigríður Halldórsdóttir, prófessor í hjúkrunarfræði,  
Háskólinn á Akureyri, Sólborg v/Norðurslóð  
Pósthólf 224, 602 Akureyri  
Vs: 460 8000. Netfang: sigridur@unak.is

Ef þú vilt fá meiri upplýsingar eða hefur áhuga á þátttöku hringdu í Áslaugu Birnu Ólafsdóttir í síma 555 0537 og 690 4733. Einnig er hægt að fá sent upplýsingablað.

Ef þú hefur samband þá ertu ekki að skuldbinda þig til þátttöku, heldur aðeins að lýsa yfir áhuga á því að fá meiri upplýsingar.

Með kærri kveðju og von um góðar undirtektir

---

Áslaug Birna Ólafsdóttir,  
hjúkrunarfræðingur  
Sími: 555 0537 og 690 4733  
Miðvangi 109, 220 Hafnarfjörður

---

Sigríður Halldórsdóttir  
prófessor  
Netfang: [sigridur@unak.is](mailto:sigridur@unak.is)  
Háskólinn á Akureyri



## **Appendix VII**

**Information about the study to the co-researchers – English version/Icelandic version**



## Information sheet

### Being a child with attention deficit and hyperactivity Research January 2006-January 2007

**Research supervisor:**  
**Sigríður Halldórsdóttir, Professor of Nursing,**  
**University of Akureyri, Sólborg v/Norðurslóð**  
**PO Box 224, 602 Akureyri**  
**Work phone: 460 8000, E-mail: sigridur@unak.is**

This information is for boys and girls with ADHD aged 11-16, and their parents.

Read the information carefully before you decide whether to take part in the study.

My name is NN and I am a nurse. I am also studying for an MSc degree at the Royal College of Nursing in London/Manchester University, in collaboration with the University of Akureyri. This research is for my MSc dissertation.

I worked for many years as a school nurse, and met boys and girls with ADHD. I feel that people often know little about ADHD, and that they don't understand how boys and girls with ADHD feel. In this research I am going to listen to boys and girls talk about their experience of having ADHD.

The objective of the research is to help families, friends and people who work with children and teenagers to know more about ADHD, and understand better what it is like to have ADHD. The objective is also for people to find out what is most helpful for you.

About ten girls and boys will be included in the study. We will meet once or twice during 2006 and talk for about an hour at a time. You and your parents will decide where we meet. It could be e.g. at your home, or at the **ADHD association**, or somewhere else.

I hope you will find it good to talk to me. Many people find it good to talk about their experience. But some people may feel bad when they talk

about their experiences. If you feel bad after the interviews you can talk to Susan an educational and advisory service on parenting and mental health of children and adolescents, tel: xxxxxxxx. Susan has nothing to do with the research, and she won't tell me what you say to her. I hope you will enjoy helping me in my research. And I hope that the research will help children and teenagers with ADHD in the future, so people will understand them better, and can help them more. Maybe something in the results of the research will help you, too.

Because so few people live in Iceland, there is always some risk that people in research will be recognised. I will do all in my power to make sure you are not recognised in the study. I will tape the interviews and type them up myself. I will keep the tapes and all the information in a locked cupboard in a safe place. When I type up the interview, I will use another name for you, and no names of people or places will be included. I am the only person who has access to the tapes and what I type up. In the manuscript of my dissertation I will not describe any events or circumstances that can be traced to you. When the research is complete I will destroy the tapes. I will not tell anyone what you say in the study. If your parents or anyone else want information from our conversations, they must ask you directly.

The **ADHD Association** is helping me advertise for children for the research. And if necessary I can ask other nurses to advertise for participants. Those who are interested in taking part in the research should ring me. Your parents are welcome to meet me first, to get to know me, before you decide whether you want to take part in the research. Both you and your parents must consent to your talking to me. If a large number of people contact me, I shall choose who is to participate in the study. For instance, it is important that both boys and girls get to talk about their experience, and also youngsters from outside the capital area.

You yourself decide whether you want to take part in the research. Even if you say "yes" you can stop at any time without any explanation. Even if you stop, it will not affect the service you receive, e.g. from the school nurse or other health workers. If you want to stop the conversation, or stop for a rest, you can simply say so and we will stop, If you don't want to answer a question, just say "pass." You do not have to tell me anything unless you yourself want to.

If you are interested in taking part in the research and want to tell me about your experience, or if you have any questions, please ring one of the telephone numbers below.

With thanks in advance

---

NN, nurse  
Tel: xxxxxxxx  
Address:

---

Prof. Sigríður Halldórsdóttir,  
e-mail: sigridur@unak.is  
University of Akureyri

*If you have any questions about your rights as a participant in scientific research, or if you wish to withdraw from participation in the research, you can contact the Bioethics Committee, Vegmúli 3, 108 Reykjavík. Tel: 551-7100, fax: 551 1444*



Að vera barn með ofvirkni og athyglisbrest  
Rannsókn  
Janúar 2006-Janúar 2007

Ábyrgðarmaður rannsóknarinnar:  
Sigríður Halldórsdóttir, prófessor í hjúkrunarfræði,  
Háskólinn á Akureyri, Sólborg v/Norðurslóð  
Pósthólf 224, 602 Akureyri  
Vs: 460 8000. Netfang: sigridur@unak.is

Þessar upplýsingar eru fyrir stáka og stelpur með ADHD 11-16 ára og foreldra þeirra.

Lesið þær vel áður en þið ákveðið hvort þið viljið taka þátt í rannsókninni.

Ég heiti Áslaug Birna Ólafsdóttir og er hjúkrunarfræðingur. Ég er líka nemandi í meistaranámi í hjúkrunarfræði við Royal College of Nursing í London/Manchester háskóla sem er í samstarfi við Háskólann á Akureyri. Þessi rannsókn er lokaverkefnið mitt í meistaranáminu.

Ég vann í mörg ár sem skólahjúkrunarfræðingur og hitti stelpur og stráka með ADHD. Mér finnst fólk oft ekki vita mikið um ADHD og ekki skilja hvernig stelpum og strákum með ADHD líður. Í þessari rannsókn ætla ég að hlusta á stráka og stelpur með ADHD og skrifa um þeirra reynslu.

Rannsóknin er gerð til að fjölskyldur, vinir og þeir sem vinna með börnum og unglingum viti meira og skilji betur hvernig það er að vera með ADHD. T.d. er mikilvægt að fólk fái að vita hvað það er sem hjálpar ykkur best.

Um það bil tíu stelpur og strákar verða í rannsókninni. Við hittumst 1-2 sinnum á árinu 2006 og tölum saman í um það bil 60 mínútur í einu. Þið og foreldrar ykkar ákveðið staðinn þar sem við tölum saman. Það getur t.d. verið heima hjá ykkur eða einhvers staðar annars staðar.



555 0537 og 690 4733. Ef þú hefur samband þá ertu ekki að skuldbinda þig til þátttöku, heldur aðeins að lýsa yfir áhuga á því að fá meiri upplýsingar.

Með fyrirfram þökk

---

Áslaug Birna Ólafsdóttir,  
hjúkrunarfræðingur  
Sími: 555 0537 og 690 4733  
Miðvangi 109, 220 Hafnarfjörður

---

Sigríður Halldórsdóttir  
prófessor  
Netfang: sigridur@unak.is  
Háskólinn á Akureyri

*Ef þú hefur spurningar um rétt þinn sem þátttakandi í vísindarannsókn eða vilt hætta þátttöku í rannsókninni getur þú snúið þér til Vísindasiðanefndar, Vegmúla 3, 108 Reykjavík. Sími: 551-7100, fax: 551 1444*

## **Appendix VIII**

**Notification to the Data Protection Authority – English version/Icelandic  
version**



Áslaug Birna Ólafsdóttir  
Miðvangi 109  
220 HAFNARFIRÐI



Persónuvernd

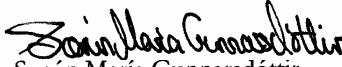
Rauðarástíg 10 105 Reykjavík  
sími: 510 9600 bréfasími: 510 9606  
netfang: [postur@personuvernd.is](mailto:postur@personuvernd.is)  
veffang: [personuvernd.is](http://personuvernd.is)

Reykjavík, 18. apríl 2007  
Tilvísun: 2007040332 SMG/--

It is hereby confirmed that Áslaug Birna Ólafsdóttir has complied with her duty of notification to the Data Protection Authority (DPA) in Iceland, as required by Art. 31 of Act no. 77/2000, on the Protection of Individuals with regards to the Processing of Personal Data.

The notification received the number S2768/2006 and has been published in the public register of received notifications, accessible on the DPA website, [www.personuvernd.is](http://www.personuvernd.is).

Respectfully,

  
Særun María Gunnarsdóttir  
Legal Counsel

<b>Notification of processing of personal data</b>	<b>No. S2768</b>
New notification or notification of changed processing?	New notification
Prior notification no. if amending prior notification:	
Name	Áslaug Birna Ólafsdóttir
Name of representative (e.g. director) <b>if responsible party is a company/agency:</b>	
Name of notifier:	Áslaug Birna Ólafsdóttir
Address:	Miðvangur 109
Postcode:	220
Place:	Hafnarfjörður
Tel. no. of contact:	6904733
Title of project (e.g. name of document or of study project)	Lived experience of children and adolescents with Attention Deficit /Hyperactivity Disorder (ADHD): A phenomenological study
What is the purpose of the processing?	MSc research in nursing
What information will be acquired/processed?	Lived experience of children and adolescents with Attention Deficit /Hyperactivity Disorder (ADHD)
Whence will the information be acquired?	Dialogues with children/adolescents age 11-16 with ADHD
Authority for processing of personal data as provided in art. 8 of the Act on the Protection and Processing of Personal Data:	Consent of the data subject, cp. item 1.

Will sensitive personal data as provided in item 8, art. 8 of the Act, be processed?	No
Further conditions for processing of sensitive personal data as provided in art. 9 of the Act?	
Further details of the authority cited above, e.g. legal provisions or, if based on informed consent, detail the content of the consent form).	Informed consent: Both parents and child give written consent for the child to participate in a dialogue to explore the child's experience of living with ADHD. The purpose of the study and the research question are specified. The child may withdraw from participation at any time, without giving any explanation. Confidentiality is guaranteed, as is complete anonymity.
If personal data are acquired from other sources than the data subject, it must be stated how the duty to inform the data subject is to be carried out, as provided in art. 21 of the Act.	Not applicable
If personal data are elicited from the data subject him/herself, how are requirements of information met, cp. Art. 20 of the Act?	Not applicable
Will personal data be gathered by use of CCTV or other monitoring devices?	No
Will data be passed to others? To whom?	No
Will data be taken out of the country?	No
Will data appear on the Net/Worldwide Web?	No
What security measures will be applied?	Obliteration of personal identification

If other, what?

Name and/or job title of the person responsible for the above security measures

Áslaug Birna Ólafsdóttir, nurse  
Sigríður Halldórsdóttir, professor

Will data/identification be obliterated, and if so when?

On completion of processing, 2007

Will another party (processing party) be assigned to work with the data under a contract?

No

ID no. of processing party

Name of processing party:

Address of processing party:

Postcode:

Place:

What are the obligations of the processing party under this agreement ?

Other observations from the notifier:

Áslaug Birna Ólafsdóttir

Miðvangi 109  
220 Hafnarfjörður



Persónuvernd

Rauðarárstíg 10 105 Reykjavík  
sími: 510 9600 brefasími: 510 9606  
netfang: postur@personuvernd.is  
veffang: personuvernd.is

Reykjavík 3. janúar 2006  
Tilvísun: S2768/2006/ EB/-

Hér með staðfestist að Persónuvernd hefur móttengið tilkynningu í yðar nafni um vinnslu persónuupplýsinga. Tilkynningin er nr. S2768/2006 og fylgir afrit hennar hjálagt.

Allar tilkynningar sem berast Persónuvernd birtast sjálfkrafa á heimasíðu stofnunarinnar. Tekið skal fram að með móttöku og birtingu tilkynninga hefur engin afstaða verið tekin af hálfu Persónuverndar um efni þeirra.

Virðingarfyllst,

  
Erla Björgvinsdóttir

Hjál.:

- Tilkynning nr. S2768/2006 um vinnslu persónuupplýsinga.

**Tilkynning um vinnslu  
persónuupplýsinga**

Tilkynning móttækin: 20.12.2005 18:15:12

Númer S2768

Er um að ræða nýja tilkynningu eða  
breytingu á eldri tilkynningu?

☒ Ný tilkynning

☐ Tilkynning um breytingu

Eldra tilkynninganúmer sé um breytta  
tilkynningu að ræða:

Kennitala ábyrgðaraðila:

1706605959

Nafn forsvarsmanns (s.s. forstjóra) ef  
ábyrgðaraðili er  
fyrirtæki/stofnun:

Áslaug Birna Ólafsdóttir

Nafn þess sem fyllir tilkynninguna út:

Nafn:

Áslaug Birna Ólafsdóttir

Heimilisfang:

Miðvangi 109

Póstnúmer:

220

Staður:

Hafnarfjörður

Símanúmer tengiliðs :

6904733

Titill verkefnis  
(ss. nafn á skrá eða heiti rannsóknar)

Upplifun barna og unglunga af þeirri reynslu að lifa með ADHD:  
Fyrirbærafræðileg rannsókn.

Tilgangur vinnslunnar?

MSc rannsókn í hjúkrun

Hvaða upplýsingar verður unnið með?

Reynsla barna og unglunga með Attention Deficit /Hyperactivity  
Disorder (ADHD)

Hvert verða upplýsingarnar sóttar?

Samtöl við börn/unglinga 11-16 ára með ADHD

Heimild(ir) til vinnslu  
persónuupplýsinga, sbr. 8. gr. laga um  
persónuvernd og meðferð  
persónuupplýsinga:

☒ samþykki hins skráða sbr. 1. tl.

☐ nauðsyn vegna samnings sbr. 2. tl.

☐ nauðsyn til að fullnægja lagaskyldu sbr. 3 tl.

☐ nauðsyn til að vernda hagsmuni hins skráða sbr. 4. tl.

☐ nauðsyn vegna almannahagsmuna sbr. 5. tl.

☐ nauðsyn til að gæta lögmætra hagsmuna sbr. 7. tl.

Verður unnið með viðkvæmar  
persónuupplýsingar, sbr 8. tl. 2. gr.  
laganna?

Nei

Viðbótarskilyrði um vinnslu viðkvæmra  
persónuupplýsinga, sbr. 9. gr. laganna:

	<input type="checkbox"/> upplýst og skriflegt samþykki hins skráða sbr. 1.tl. <input type="checkbox"/> sérstök lagaheimild sbr. 2. tl. <input type="checkbox"/> skylda skv. samningi aðila vinnumarkaðar sbr. 3. tl. <input type="checkbox"/> nauðsyn til að vernda hagsmuni hins skráða sbr. 4. tl. <input type="checkbox"/> nauðsyn vegna reglubundinnar starfsemi sbr. 5. tl. <input type="checkbox"/> hinn skráði gerir upplýsingar opinberar sbr.6. tl. <input type="checkbox"/> vegna dómsmáls eða annara laganauðsynja sbr. 7. tl. <input type="checkbox"/> nauðsyn vegna lækni meðferðar/stjórnsýslu sbr.8. tl. <input type="checkbox"/> nauðsyn vegna tölfræði-/vísindarannsóknar sbr. 9. tl. <input type="checkbox"/> lögmæt vöktun skv. 2.mgr.
<p>Frekari skýringar á þeim heimildum sem merkt er við hér að ofan (t.d. lagaákvæði eða ef byggt er á samþykki hins skráða skal hér greint frá efni samþykkisýfirlýsingar)</p>	<p>Upplýst samþykki: Bæði foreldrar og barn samþykkja skriflega að barnið taki þátt í viðtali þar sem reynsla af því að lifa með ADHD er skýrð. Skýrt er frá tilgangi rannsóknarinnar, rannsóknarspurningu. Barnið getur hætt þátttöku hvenær sem er án nokkurrar skýringar. Trúnaði er heitið og algjörri nafnleynd. Þátttakandi leyfir að viðtölin séu tekin upp á segulband. Eyðslu gagna er lofað að vinnslu lokinni.</p>
<p>Ef aflað er persónuupplýsinga frá öðrum en hinum skráða, hvernig er þá uppfyllt viðvörðunarskylda gagnvart hinum skráða, sbr. 21. gr. laganna</p>	<p>Ekki gert</p>
<p>Ef aflað er persónuupplýsinga frá hinum skráða sjálfum, hvernig er þá uppfyllt fræðsluskylda, sbr. 20. gr. laganna</p>	<p>Ekki gert</p>
<p>Verður persónuupplýsingum safnað með notkun eftirlitsmyndavéla eða annars konar vöktunarbúnaðar?</p>	<p>Nei</p>
<p>Verða upplýsingarnar afhentar öðrum. Hverjum?</p>	<p>Nei</p>
<p>Verða upplýsingarnar fluttar úr landi?</p>	<p>Nei</p>
<p>Verða upplýsingarnar birtar á Netinu / Vefnum?</p>	<p>Nei</p>
<p>Hvaða öryggisráðstafanir verða viðhafðar?</p>	<p> <input type="checkbox"/> Aðgangsorð  <input type="checkbox"/> Dulkóðun  <input checked="" type="checkbox"/> Afmáun persónuauðkenna  <input type="checkbox"/> Annað  Ef annað. þá hvað? </p>
<p>Nafn og/eða stöðuheiti þess sem ber ábyrgð á framangreindum öryggisráðstöfunum</p>	<p>Áslaug Birna Ólafsdóttir hjúkrunarfræðingur/ Sigríður Halldórsdóttir prófessor</p>
<p>Verður upplýsingunum/auðkennunum eytt og þá hvenær?</p>	<p>Þegar úrvinnslu er lokið 2007</p>
<p>Verður öðrum aðila (vinnsluaðila) með skriflegum samningi falin vinnsla upplýsinganna?</p>	<p>Nei</p>
<p>Kennitala vinnsluaðila</p>	
<p>Nafn vinnsluaðila</p>	

Heimilisfang vinnsluaðila

Póstnúmer:

Staður:

Hverjar eru skyldur vinnsluaðila  
samkvæmt þessum samningi?

Aðrar athugasemdir tilkynnanda:

Sent til



## **Appendix IX**

**Informed consent form – English version/Icelandic version**



## Informed Consent

### Title of study:

The lived experience of children and adolescents living with ADHD:  
A phenomenological study

The objective of the study is to help people to know more about ADHD and understand better what it is like to be a child/teenager with ADHD. The objective is also for people to find out what is most helpful for children/teenagers with ADHD.

I have read the information sheet about the study.

I have decided to take part in this study. I give Áslaug Birna permission to ask me questions and discuss with me my experience of having ADHD.

I myself decide whether I want to take part in the study. Even if I say "yes" I can stop at any time without any explanation. I can stop an interview if I wish. Even if I stop, it will have no effect on the service I receive, e.g. from the school nurse or other health workers. I do not have to say anything unless I myself want to.

I have been promised complete confidentiality, and my name will not appear in the typed conversations, nor in the dissertation manuscript. In the dissertation no events or circumstances will be described which could be traced to me. NN will not permit any other person to have access to the conversations or information from them. If my parents or others wish to have information from the conversations, they must ask me directly.

I permit NN to use my words and sentences in her research, provided that my name appears nowhere, and that nothing in the study will be traceable to me.

Date\_\_\_\_\_

Name and ID no. of participant/child

\_\_\_\_\_

Name of  
parent

\_\_\_\_\_

Name of party submitting informed consent  
form

\_\_\_\_\_



## Upplýst samþykki

Heiti rannsóknarinnar:  
Upplifun barna og unglunga af þeirri reynslu að lifa með ADHD:  
Fyrirbærafræðileg rannsókn.

Rannsóknin er gerð til að fjölskyldur, vinir og þeir sem vinna með börnum og unglingum viti meira og skilji betur hvernig það er að vera með ADHD. T.d. er mikilvægt að fólk fái að vita hvað það er sem hjálpar strákum og stelpum með ADHD.

Ég hef lesið upplýsingatexta um rannsóknina.

Ég hef ákveðið að taka þátt í þessari rannsókn. Ég gef Áslaugu Birnu leyfi til að spyrja mig spurninga og ræða við mig um mína reynslu af því að vera með ADHD.

Ég ákveð sjálf/sjálfur hvort ég vilt taka þátt í rannsókninni. Þó ég segi 'já' get ég hætt hvenær sem er án þess að útskýra það nokkuð. Ég get hætt í samtalinu ef ég vil. Þó ég hætti hefur það engin áhrif á það hvernig þjónustu ég fæ t.d. frá skólahjúkrunarfræðingi eða öðrum heilbrigðisstarfsmanni. Ég þarf ekki að segja neitt nema ég vilji það sjálf/sjálfur.

Mér hefur verið lofað fyllsta trúnaði og nafnið mitt kemur hvergi fram, hvorki í hinum vélrituðu samtölum né heldur í handriti rannsóknarinnar. Í handriti rannsóknarinnar verður ekki lýst atvikum eða aðstæðum sem hægt er að rekja til mín. Áslaug Birna gefur engum aðgang að samtölunum eða upplýsingar úr þeim. Vilji foreldrar mínir eða aðrir fá upplýsingar úr samtölunum verða þeir að leita beint til mín.

Ég veiti Áslaugu Birnu leyfi til að nota mín orð og setningar í rannsókninni enda kemur nafnið mitt hvergi fram og ekki hægt að rekja neitt í rannsókninni til mín.

Dagsetning\_\_\_\_\_

Nafn og kennitala  
þátttakanda/barns\_\_\_\_\_

Nafn  
foreldris\_\_\_\_\_

Nafn þess sem leggur yfirlýsinguna  
fyrir\_\_\_\_\_

## **Appendix X**

### **Declaration from the English translator**

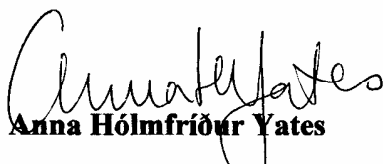
22 April 2007

## **Declaration**

I hereby confirm that I have translated the appendices to Áslaug Birna Ólafsdóttir's dissertation:

**The lived experience of children and adolescents living with ADHD:  
A phenomenological study**

Sincerely



**Anna Hólmfríður Yates**

**Certified translator**

Langholtsvegur 172

Reykjavík

Iceland

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